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Life-Sustaining Technologies and the Elderly

Summary

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Foreword

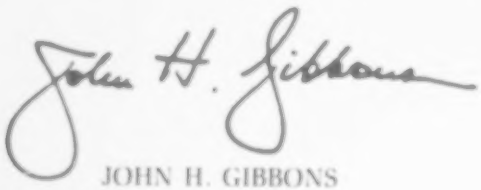
In September 1984, OTA received requests from both the House and Senate Aging Committees to study the implications for their constituents of medical technologies that can sustain life in patients who are critically or terminally ill. Both Committee Chairmen, Senator John Heinz and Congressman Edward Roybal, expressed concern about elderly persons whose rights as patients and dignity as citizens are, or are feared to be, jeopardized—either by unwanted aggressive medical treatment or, conversely, by financial barriers to treatment.

The Senate Special Committee on Aging cited "new questions about the quality of life" that accompanies increased survival made possible by "current and emerging methods of life support." The Committee requested a "thorough review of the ethical dilemmas concerning life and death decisions that are faced by health care practitioners, elderly patients themselves, and concerned family members." OTA was asked to explore the special problems related to treatment decisions for older patients who are cognitively impaired and, thus, unable to make their own decisions, and to compare alternate methods for specifying in advance one's wishes regarding treatment. The Senate Committee also expressed interest in comparative reviews of the various institutional and noninstitutional settings in which life-sustaining technologies are used.

The House Select Committee on Aging identified as the key issues those related to "financial access" to life-sustaining technologies and the "right to choose." Of special interest were ways to ensure that elderly persons retain autonomy in treatment decisions, and the roles of families, providers, and government in supporting patient autonomy. Ethical issues related to the use of technologies that are currently available or anticipated were to be reviewed to advance understanding about care of the critically and terminally ill elderly. OTA was asked to assess the costs to patients, their families, and the public, and to lay the groundwork for policies about Medicare and Medicaid reimbursement of these technologies. Also of interest to the House Committee were the growing use of home care and issues related to quality of care, especially in the home.

In response, OTA has conducted a study of a wide range of topics, some of which have recently been receiving a great deal of scrutiny inside and outside the government. In order to derive information specific enough to guide possible congressional action and to be responsive to the requesting Committees, this examination of the issues is specifically tied to *particular* life-sustaining technologies and their use with patients who are *elderly*. At the same time, much of this information is applicable to life-sustaining technology in general and to citizens of all ages.

OTA has tried to provide a strong sense of the human dimension in this report. In addition to descriptions of what is theoretically possible and statistically documentable, much information is presented about the experience of individual patients and their families. The case examples, of which there are many, are true stories. While no case is "typical," every one expresses the potential benefits or the potential burdens of life-sustaining treatments. Each makes clear and poignant the needs of patients, their families, and caregivers who are faced with decisions about—or the consequences of decisions about—the use of life-sustaining technologies.



JOHN H. GIBBONS
Director

Advisory Panel: Life-Sustaining Technologies and the Elderly

John W. Rowe, *Chairperson*
Chief, Gerontology Division, Department of Medicine
Beth Israel Hospital, Harvard Medical School

David Axelrod
Commissioner
New York State Dept. of Health

Abraham Brickner
Director, Health Services Research
and Program Development
The Cleveland Clinic Foundation

Daniel J. Callahan
Director, The Hastings Center

A. Edward Doudera
Harmon, Jones & Sanford
Camden, ME

Nancy N. Dubler
Director, Division of Legal and
Ethical Issues in Health Care
Montefiore Medical Center

Rose Goldstein
Director of Social Services
Jewish Home and Hospital for the Aged
Bronx, NY

Val J. Halamandaris
President
National Association for Home Care
Washington, DC

William A. Knaus
Director of I.C.U. Research
The George Washington University
Medical Center

Steven Lazarus
President, ARCH Development Corp.
The University of Chicago

Joanne Lynn
Associate Professor
Division of Geriatric Medicine
The George Washington University
Medical Center

Catherine P. Murphy
Associate Professor
School of Nursing
Boston College

John J. Paris
Professor
Department of Religious Studies
Holy Cross College

A-J Rock-Levinson
Executive Director
Concern for Dying
New York, NY

Anne A. Scitovsky
Chief, Health Economics Department
Research Institute
Palo Alto Medical Foundation

Victor W. Sidel
Distinguished University Professor
of Social Medicine
Montefiore Medical Center
Albert Einstein College of Medicine

R. Knight Steel
Professor of Medicine
Geriatrics Section
Boston University Medical Center

William A. Wendt
Executive Director
The St. Francis Center
Washington, DC

Terrie T. Wetle
Assistant Professor of Medicine
Division of Health Policy
Harvard Medical School

Mary Opal Wolanin
Professor Emerita
College of Nursing
University of Arizona

NOTE: OTA appreciates and is grateful for the valuable assistance and thoughtful critiques provided by the advisory panel members. The panel does not, however, necessarily approve, disapprove, or endorse this report. OTA assumes full responsibility for the report and the accuracy of its contents.

OTA Project Staff: Life-Sustaining Technologies and the Elderly

Roger C. Herdman, *Assistant Director, Health and Life Sciences Division*

Gretchen S. Kolsrud, *Biological Applications Program Manager*

Claire W. Maklan, *Project Co-Director*

Katie Maslow, *Project Co-Director*

Robert A. Harootyan, *Project Director*[1]

Gladys B. White, *Analyst*
Hindy J. Shaman, *Research Assistant*
Blake M. Cornish, *Research Assistant*
Judy K. Kosovich, *Legal Analyst*
Anne M. Guthrie, *Research Assistant*
Everett C. Hills, *Research Assistant*

Support Staff

Sharon Kay Oatman, *Administrative Assistant*
Linda Rayford, *Secretary/Word Processor Specialist*
Barbara Ketchum, *Secretary*

Kerry Kemp, *Division Editor*
Chris Elfring, *Editor*

Special Contributors

Nancy B. Cummings
Kathryn S. Aultman
Lisa J. Raines

[1]Until June 1986.

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Life-Sustaining Technologies and the Elderly

INTRODUCTION

The dramatic advances in life-sustaining medical technologies during the past three decades have been accompanied by rapid expansion in their availability and use. As equipment and procedures have been refined and experience accumulated, the necessary personnel, facilities, and reimbursement have expanded, and the clinical criteria guiding use have been broadened. The types of patients who become candidates for life-sustaining treatments have changed, and their numbers have increased sharply. Many of these patients are *elderly*. As the population ages, as once "extraordinary" measures become commonplace, and as ever-more powerful technologies emerge, it becomes increasingly important to understand the problems as well as the potential associated with the use of these technologies and to devise policies that reflect this understanding.

Technologies that support or replace the functioning of a vital organ are capable of saving and sustaining life and, sometimes, capable of restoring health and independence. However, an individual's response to treatment can seldom be predicted with certainty; thus, it is never clear that a "life-sustaining" technology will sustain the life of a particular patient or, if it does, for how long. The quality of the life that is sustained may be even harder to predict. Patients and other interested parties may evaluate differently the benefits and burdens associated with treatment versus nontreatment and with one treatment versus another. An important factor that further complicates matters is that many patients with life-threatening conditions are not able to understand their treatment options or to express preferences regarding them.

Public discussion about the use of life-sustaining technologies, either for individual cases or health care policy, is relatively new, but newsworthy. At any one time, many thousands of elderly persons are receiving life-sustaining interventions. The vast majority of cases go unnoticed except by the patients, family members, and others directly involved in making and living with difficult treatment decisions. However, a few of these cases gain notoriety and public attention as it becomes apparent either that treatment was unwanted or futile or, conversely, that some new medical breakthrough or personal triumph over adversity has occurred. Under public scrutiny, these cases make clear the interdependence of private health care decisions and the public policies that determine whether treatment choices are legal, ethically acceptable, economically feasible, and fair.

The legal, ethical, and economic questions raised by decisions about the use of life-sustaining technologies have been studied by scholars and pol-

icymakers both inside and outside the government. The first major government publications addressing access to and decisions regarding the use of life-sustaining treatment were prepared in the early 1980s by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. Related research has been performed or sponsored by the Office of the Surgeon General, the General Accounting Office (GAO), the Congressional Budget Office (CBO), the National Institutes of Health (NIH), and the Office of Technology Assessment (OTA). These studies demonstrate the lack of consensus regarding appropriate use of life-sustaining technologies and the lack of consensus even about appropriate procedures for making those decisions.

This assessment draws on the earlier studies, but it is different from them in two important respects. First, it is focused on *particular technologies*. The discussion goes beyond abstract considerations related to the care of the critically and terminally ill to identify specific problems and potential solutions related to selected technologies used to treat or manage life-threatening conditions. Second, this assessment is focused on a *specified age group, i.e., persons over age 65*, rather than on all potential patients. The major purpose is to provide an array of options for public policy that will support wiser clinical decisions about the use of these technologies. Toward this goal, the assessment presents information about topics as diverse as the cost of equipment, competing ethical principles, the experience of patients and their families, and the training of health care professionals. The assessment synthesizes available and new information, from a new perspective, and from this it develops a set of issues and related options for congressional review.

Selected Life-Sustaining Technologies

Life-sustaining technologies are drugs, medical devices, or procedures that can keep individuals alive who would otherwise die within a foreseeable, but usually uncertain, time period. While these technologies share some common ethical, legal, and health care delivery problems, each has unique characteristics that either raise special questions or suggest possible solutions. Five specific technologies used to treat or manage life-threatening conditions are the focus of this assessment:

1. **Cardiopulmonary resuscitation** (CPR) refers to a range of technologies that restore heartbeat and maintain blood flow and breathing following cardiac or respiratory arrest. Resuscitation procedures range from **basic life support**, which uses manual external cardiac massage and mouth-to-mouth ventilation, to **advanced life support**, which may include application of prescription drugs and sophisticated devices such as an electrical defibrillator, temporary cardiac pacemaker, and mechanical ventilator. Resuscitation has extremely wide potential application because it can be applied to virtually any person whose heart stops beating.
2. **Mechanical ventilation** is the use of a machine to induce alternating inflation and deflation of the lungs, to regulate the exchange of gases

in the blood. The most common type of ventilator (or "respirator") delivers inspiratory gases directly into the patient's airway through tubing that connects the patient to the machine. The technology is used to sustain patients whose spontaneous breathing is inadequate or has stopped altogether due to acute or chronic diseases of the neuromuscular, neurologic, or pulmonary system, or due to anesthesia or trauma. This assessment is particularly concerned with mechanical ventilation that becomes **prolonged** or **chronic**.

3. **Renal dialysis** is an artificial method of maintaining the chemical balance of the blood when the kidneys have failed. The blood is cleansed of impurities, either by cycling the blood through a machine and back into the patient via catheters (**hemodialysis**), or by cycling dialyzing fluid into and out of the abdomen using the patient's peritoneal membrane as a filter (**peritoneal dialysis**). Dialysis is used for patients in acute renal failure and those with chronic **end-stage renal disease** (ESRD).
4. **Nutritional support and hydration** refers to artificial methods of providing nourishment and fluids. The two modes of delivery are **enteral** (or tube feeding), in which nutritional formulas are delivered via a tube into the digestive tract, and **parenteral** that includes all methods other than enteral but is primarily intravenous feeding in which nourishment is delivered via catheter into the bloodstream. **Total parenteral nutrition** (TPN) is an intravenous procedure that supplies sufficient nutrients to maintain a person's weight indefinitely. Tube feeding and TPN are used primarily for people who are unable to take sufficient amounts of food and fluids by mouth or who are unable to digest and absorb them adequately.
5. **Antibiotics** are a large set of drugs used to cure or control numerous bacterial, viral, and fungal infections, including minor ones. Different families of antibiotics have been developed for use in combatting different types of infections. Antibiotics may be administered topically, orally, intravenously, or intramuscularly, in discrete doses or continuously. All antibiotics are potentially life-sustaining. By "life-sustaining antibiotic therapy" OTA means not a particular drug or family of drugs but the use of any antibiotic against a life-threatening infection.

With the exception of antibiotics, none of the five technologies examined in this assessment can *cure* the underlying condition that precipitated its use. Thus, among patients who receive these interventions and survive, health status and functional capacity vary widely. While some patients regain adequate natural function of the affected organ, others become permanently dependent on the life-sustaining technology (and they may be simultaneously dependent on more than one life-sustaining technology). They may require continuing medical care and, often, other forms of assistance.

The life-sustaining technologies OTA has studied are only a few of many possibilities. They were selected to illustrate significant ranges across such dimensions as burden, cost, and risk. For example, antibiotic therapy administered intravenously is relatively painless and nonrestrictive, especially in

Photo credit: Edmund G. Lowrie, National Medical Care, Inc.

This 83-year-old woman has been on dialysis for 5 years.

comparison with mechanical ventilation, hemodialysis, and TPN. Mechanical ventilation frequently involves continuous, round-the-clock application, while hemodialysis is typically applied three times per week for 3 to 5 hours per treatment. Resuscitation is, ideally, applied only once. Costs and expenditures, which are related to frequency and duration of treatment, range from minor to catastrophic. Available reimbursement may be near total or minimal. The technology may bring risks of serious complications (e.g., renal failure associated with mechanical ventilation) or, provided proper procedures are followed (e.g., to prevent catheter-related infection for TPN), it may be generally safe. While invasiveness and high cost may tend to restrict use, low risk and low cost (or generous reimbursement) may lead to overuse. All these factors bear on clinical decisionmaking.

The five technologies examined in this assessment also illustrate the variety of settings and circumstances in which life-sustaining treatment can be administered. Most of these technologies are now technically possible and available not only in acute care hospitals and intensive care units (ICUs), but in nursing homes, patients' homes, and other community settings. While intubation for mechanical ventilation is usually done by highly trained professionals in an emergency room or ICU, some stabilized ventilator patients can manage in their own homes. Basic resuscitation techniques can be performed by trained bystanders wherever a cardiac arrest occurs, but advanced CPR requires emergency transfer to a hospital.

Focus on the Elderly Population

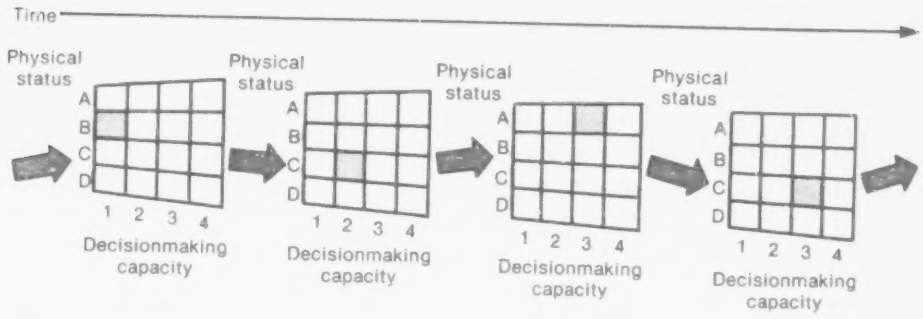
This assessment focuses on elderly persons who are already receiving or who might become candidates for life-sustaining medical technologies. For purposes of this assessment, **the elderly population is defined as all persons aged 65 and over. OTA recognizes and emphasizes, however, that defining the elderly population on the basis of any chronological age criterion tends to mask the heterogeneity of that population.** Sixty-five, or any chronological age, is a poor indicator of biological function, physiological reserve, cognitive ability, or health care needs. The use of age 65 is justified, however, by its prominence in available health and demographic statistics and its relevance to eligibility criteria in current Federal and State health care programs, especially Medicare. To minimize the loss of analytical and descriptive rigor from using a single age criterion, this assessment refers wherever possible to subgroups of the elderly population (e.g., 65 to 74, 85 and over).

While many important considerations in the use of life-sustaining technologies apply regardless of the patient's age, some factors distinguish the elderly as a special population. These include:

- Elderly people, as a group, are at greater risk of life-threatening illness than younger people.
- Because both the prevalence and severity of chronic conditions and their associated disabilities increase in old age, elderly persons who experience a life-threatening illness are more likely than younger persons to already be in a state of compromised health and reduced functioning that negatively affects their quality of life.
- Elderly people are more likely than younger adults to be victims of a dementing illness, and they have high rates of other disorders (e.g., depression, drug toxicity) that may temporarily or permanently impair their ability to make health care decisions.
- Comorbidity (the coexistence of more than one disease) and age-associated loss of function complicate the prognosis and treatment of life-threatening conditions in elderly persons.
- There are questions about the quality of health care currently available to elderly patients. Many health professionals in practice today are poorly prepared to care for seriously ill elderly people whose presentation of disease and response to treatment may differ from that of younger adults.
- As a group, elderly people utilize a large share of all health care resources and consume the largest share of public health care dollars.
- Elderly people, as the major beneficiaries of Medicare, may bear the brunt of Federal efforts to contain health care costs.
- In contrast to other segments of the population, especially newborns and young children, the law recognizes the autonomy of elderly adults.
- Elderly persons are more likely than younger adults to have contemplated the meaning and value of their life and its end.

The significance of the above factors will be heightened as the elderly population increases in absolute and relative size, and in average age. Demographers predict continuing growth of the elderly population, from

Figure 1.—Heterogeneity of the Life-Threatened Elderly



KEY

Physical status:
- A Critically ill
- B Chronically ill
- C Severely debilitated
- D Terminally ill

Decisionmaking capacity:
- 1 Capable of making decisions
- 2 Currently capable
- 3 Currently incapable
- 4 Permanently incapable

SOURCE: Office of Technology Assessment, 1987.

approximately 25.5 million people and 11 percent of the U.S. population in 1980 to 35 million and 13 percent in 2000. Moreover, conservative projections indicate that the population aged 75 to 84, which accounted for 30 percent of the total elderly population in 1980, will reach 35 percent in 2000. During the same period, the proportion of persons 85 and older will increase from 9 to 15 percent of the population over 65.

Who Are the Life-Threatened Elderly?

In order to emphasize the diversity of the population at risk and to illuminate problems in making decisions about their care, OTA has devised a classification system consisting of four categories of "physical status" and four categories of "decisionmaking capacity." Most of these categories are not articulated in practice, but they influence a person's ability to make treatment decisions for himself or herself and may also influence the decisions that are made by others on a person's behalf.

Variation in Physical Status

A life-threatening condition may be—and in elderly persons frequently is—superimposed on preexisting physical and/or mental disorders, or it may occur in an otherwise healthy and active individual. **It is inappropriate for clinical decisionmakers or public policymakers to lump together all elderly persons who become candidates for life-sustaining technologies. Rather, the life-threatened elderly should be seen as individuals with widely varying physical and mental status.** Physical conditions may be acute or chronic, have different prognoses (both of survival and restoration of functional ability), and have a course that is either decisive or unknown.

1. **Critically ill** persons are those in the midst of an acute life-threatening episode (e.g., cardiac arrest, stroke) or persons believed to be in immi-

nent danger of such an episode. They are medically unstable, and if they are not treated, are expected to decline.

2. **Chronically ill** persons have one or more chronic conditions that may or may not be life-threatening but that reduce chances of recovery and restoration of function in the event of an acute disease. Included in this group are persons who have a life-threatening chronic condition that has been stabilized, with or without a life-sustaining technology, or that is in remission (e.g., chronic renal failure treated with dialysis; cancer in remission). Many chronic conditions that are not immediately life-threatening are mildly or severely debilitating; some (e.g., hypertension) increase the risk of acute life-threatening illnesses or the risk of complications associated with acute disease.
3. **Severely debilitated** persons have serious or multiple impairments or comorbidities. Their functional capacity and physiological reserve are severely compromised. They are medically stable but highly vulnerable to new physiological stresses (e.g., at heightened risk of infections, iatrogenic illness, complications of treatment, and accidents).
4. **Terminally ill** individuals are those for whom a prognosis of death has been made. Designation as terminally ill usually requires diagnosis of an illness that has a predictably fatal progression that cannot be stopped by any known treatment.

A widely accepted definition of "terminal illness" includes the expectation that death will occur within 6 months. This definition has been adopted by Medicare. In practice, however, accurate prognosis is extremely difficult, and this difficulty adds to the dilemmas regarding treatment decisions. Contrary to popular belief, a terminal illness is not always identifiable as such, and most patients who are *dying* have not been declared "terminally ill." Only retrospectively can these designations be reliably made.

Variation in Decisionmaking Capacity

Cognitive ability has two elements of special importance in the context of this assessment. First, a person may be cognitively normal and fully capable of making decisions, severely cognitively impaired and completely incapable of making decisions, or somewhere in between; thus, there are differences in the *boundaries* or *content* of cognition. A person who is confused or disoriented to time and place, or even judged by a court to be incompetent,[1] may still be capable of making and expressing preferences regarding his or her medical treatment. It is this relatively narrow conception of cognitive ability, i.e., **decisionmaking capacity with respect to medical treatment**, that is central to this report. A second important element of cognitive ability is *temporal*. Like physical status, cognitive ability may be stable or fluctuating, and a person's decisionmaking capacity may be expected to improve or worsen. These distinctions result in four theoretical categories of patients, as follows:

1. Individuals may be **capable of making decisions** about their medical

[1]In this assessment, OTA uses the term "incompetent" specifically to designate an assessment of cognitive ability that has been declared by a legal procedure.

care (and all other aspects of their life), and their decisionmaking capacity may be assumed to be *stable*.

2. Individuals may be **currently capable** of making decisions about their medical care, but this status is assumed to be unstable or declining. Persons whose lucidity fluctuates and those with progressive dementing disorders are examples.
3. Individuals may be **currently incapable** of making decisions, but it is expected that their decisionmaking capacity will be restored. This category includes patients who are unconscious, severely depressed or confused due to *reversible* causes (e.g., anesthesia, drug toxicity, pain).
4. Individuals may be **permanently incapable** of making decisions about their medical care (and everything else). In these persons, there is no sign of ability to absorb and evaluate information or to express a preference, and there is no realistic prospect of change. Examples include patients in a persistent noncognitive state, irreversible coma, and persons who are severely demented.

Combining the physical status categories with the decisionmaking capacity categories produces a paradigm of 16 patient groups. However, an individual's placement in this scheme is subject to change (see fig. 1). This complexity accounts, in part, for the problems inherent in generalizations about the use of life-sustaining technologies.

The combination of a patient's physical and mental status may affect both the decisionmaking process and the decision that is reached. For example, in some States, a patient's request for nontreatment is granted only if the patient is deemed *both* decisionally capable and terminally ill. Or, a critically ill patient, regardless of decisionmaking capacity, might be excluded from the decisionmaking process because of the need for immediate action.

Accurate evaluation of decisionmaking capacity is critical, but problematic. Assessment procedures are not reliable and not necessarily comparable as applied in different institutions. Assessment of cognitive status may be particularly difficult when the patient's physical status is reduced by illness, drugs, or other medical interventions, or when the patient is depressed. Patients whose ability to communicate is impaired or unstable present added problems for accurate assessment.

BACKGROUND

The findings presented in this chapter should be understood in relation to the various social phenomena that made an assessment of life-sustaining technologies timely in the first place. The historical context of this study is a stressful one, in which many things are changing rapidly and dramatically. The speed of technological advance is *unprecedented*, the elderly population is growing *geometrically*, health care is being *transformed*. The words and concepts that are part of this scenario—quality of life, autonomy, euthanasia, suicide, rationing, doctor-patient relationship, malpractice, old age—evoke strong, often conflicting, responses. Other important concepts are distinguished by their unfamiliarity: advance directive, living will, durable power of attorney, surrogate decisionmaker, prospective pay-

ment system, brain death. In this fluid environment, lags are inevitable: between new knowledge and its adoption, between technical capability and decisionmaking guidelines, between medical practice and legal protections.

In other parts of this report (especially chs. 2, 3, and 4), many of these concepts and trends are discussed in depth. They arise in the context of patients' legal rights and ways to exercise them; the cost of health care and efforts to contain them; how medical technologies are developed and accepted into practice; ethical bases for allocating health care resources; ethical and legal issues concerning the withholding and withdrawal[2] of treatments that sustain life; increased presence of the law and economics in medical practice; attitudes about illness, death, and dying; growth of the elderly population; and the emergence of geriatrics as a specialty within medicine, nursing, and other health professions. The background information presented in this chapter only suggests the range and importance of the social issues that drive concern about life-sustaining technologies.

The Specter of Rationing

The looming national debt and efforts to reduce it draw public attention to and impose new constraints on older questions about the allocation of public resources in general and health care resources in particular. At the global level, the total resource pool must be divided among all competing national interests, i.e., health, defense, education, foreign aid, the environment, crime, and so on. At the next level, health care resources (including financial, human, and technological resources) must be allocated among a myriad of potential beneficiaries and causes. Here the competition is between prevention and cure, acute care and long-term care, research and services, etc. Finally, at the micro-allocation level, specific health care resources must be distributed among the individuals who claim them. If there are 3 beds in an ICU and 4 patients, or 10 donor kidneys and 20 patients awaiting transplantation, difficult decisions must be made. At every level, our current fiscal consciousness intensifies the need to make wise choices—and to be able to demonstrate the benefits.

Many people see the present economic climate as a harbinger of inevitable rationing of scarce resources. In some circles, there is discussion of explicit criteria for allocating resources based, for example, on age, prognosis, or cost. Elsewhere, rationing is rejected outright as unnecessary and/or evil. Other solutions can be found, it is argued, if priorities are adjusted at the global level and demand for health care resources is modified (e.g., by improving disease prevention and eliminating the use of unnecessary medical procedures). Whether one favors or abhors health care rationing—or believes it is already here—the strong reaction this concept evokes is one of the major reasons for concern about high-technology health care.

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[2]In this assessment, "withholding" is a decision to not initiate a life-sustaining intervention for a particular patient. Withholding may be the enactment of the patient's express wishes or the judgment of other persons that the application of medical technology is not warranted. "Withdrawal" means the discontinuance or removal of a life-sustaining intervention that has been initiated.

The "High Cost of Dying"

Considerable attention has been drawn to the high cost of health care for the elderly population (in 1984, annual personal health care expenditures for Americans over 65 were projected at $120 billion, almost half of which would be paid by Medicare) and, in particular, to high Medicare expenditures for patients in the last year of life. The latter has been interpreted and widely referred to as the "high cost of dying." The implication has been that a great deal of money, in fact "too much" money, is spent on patients who are elderly, and too much of this on patients who *die anyway*. These figures have captured considerable attention and led many people to ask whether the benefits justify the cost. Further, because it is widely assumed that life-sustaining technologies are a major factor in the cost of care for persons who die, the value of this kind of treatment is often questioned. Projected increases in the elderly population and the increased costs these portend intensify the debate about what level of care is to be provided at public expense.

Concern about the "high cost of dying" persists despite recent analyses that put this cost in a different perspective. First, understandably, the cost of care is highest for people who get the most care, that is, those who are the sickest. Thus, what some decry as the high cost of dying others recognize as simply the cost of health care for very sick people, some of whom live, some of whom die, and many of whom are elderly. Equally important, analyses of Medicare expenditures show that the majority of elderly people who die do not incur high Medicare costs in their final year. And, of those elderly patients whose health care costs are very high, while approximately half die, the other half survive. Analysis of Medicare expenditures over the past 20 years also shows that the rate of increase has been about the same for patients who survive as for those who die, suggesting that the increase in expenditures is not due to disproportionate use of expensive life-sustaining technologies for those who die.

In 1983, to contain high Medicare expenditures, Congress mandated a new basis for payment of inpatient hospital claims. Under Medicare's Part A prospective payment system (PPS), payment for inpatient hospital care is based on predetermined amounts for patients in given diagnostic categories. Hospitals thus may show profit or loss, depending on their ability to keep their costs within the established payment limits. Hospitals and the physicians they employ now have strong economic incentives to be more selective in the type, amount, or duration of treatment provided to Medicare patients, especially those whose cost of care is likely to exceed available payment. Early studies of the effects of PPS reveal that the average length of stay in hospitals has continued its pre-PPS decline. While the potential cost savings to Medicare are significant, serious questions have been raised about possible negative effects on access to and the quality of care.

Quantity v. Quality of Life

Advances in medical technologies provide considerable ability to alter the timing and circumstances of death. Indeed, modern diagnostic and ther-

apeutic technologies have changed the very definition of death and have influenced both professional and popular expectations. Recognition of the manipulability of death enables us to presume a significant measure of control and to contemplate a death that is more or less "acceptable."

Questions about life-sustaining medical care frequently revolve around judgments about what constitutes acceptable "quality of life" (and, implicitly at least, "quality of death") and deep-seated beliefs about the relevance of this consideration. Evaluations of "quality" are subjective and personal; what is an acceptable quality of life to one person may be a fate "worse than death" to another. Similarly, life-sustaining treatment that some would gladly endure, others would reject as "too burdensome" or "undignified." Thus, it is clear that references to the quality of life must distinguish whether the referrent is the patient's unique experience and evaluation of their own life or the vicarious experience and assumptions of some other person.

Many people believe that life, whatever its quality, is sacrosanct. Under this view, the possibility of sustaining life justifies, or even dictates, the use of all potentially effective means. In contrast, many other people believe that the present and expected future quality of life are valid, even essential, considerations in decisions about whether or not to apply life-sustaining treatments. These fundamental disagreements about quality v. quantity are frequently expressed in the terms of treatments that "prolong life" v. treatments that "prolong dying." In fact, the distinction between prolonged life and prolonged dying is like the difference between the proverbial glass that may be seen either as half full or half empty. The actual referrents are the same. (In this assessment, OTA uses the terms "prolonged life" and "prolonged dying" only when quoting other sources.)

Accompanying new attitudes toward death, and contributing to them, is the dramatic shift in the place of death. While the majority of deaths used to occur at home, by 1984, 61 percent of all deaths in this country occurred in hospitals and other medical centers. This shift has major implications for the types of care available to patients, the identity and number of persons involved in their care, and the kinds of decisions that must be made. Ironically, while hospitals were once feared as "places to die" because so little could be done to avert death, some people now fear hospitals as places to die because so *much* can be done.

SELECTED FINDINGS

Summarized below are the findings OTA deems most significant either because they relate uniquely to elderly persons, affect large numbers of citizens, have legislative implications, or make original contributions to the debate about life-sustaining technologies. The findings are presented under four general categories: 1) current and future resource use; 2) quality of care; 3) access to care; and 4) decisionmaking problems and processes. Further information on all these topics, as well as many more specific findings, appear in chapters 2 through 10 of the full report and in associated background papers.

For the most part, the findings presented here apply to all of the technologies OTA studied—but they would not have been evident, or not docu-

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mentable—without focusing on individual technologies. Thus, an overriding conclusion of this project is that **assessments of individual technologies can provide information for both public policy and clinical decisionmaking that abstract considerations of life-sustaining technology cannot.** Future studies and debate about health care decisionmaking might usefully adopt this more focused approach.

Current and Future Resource Use

FINDING: Data on current utilization of life-sustaining technologies are highly unreliable. Future utilization cannot be accurately predicted.

OTA's attempt to estimate the utilization of five life-sustaining technologies reveals, above all, shortcomings in the available data and existing data collection systems. With the exception of the data collected and maintained by the Health Care Financing Administration (HCFA) on Medicare's End Stage Renal Disease program, reliable data on the numbers of patients are not available.

Estimates of the total number of patients of all ages and the number of elderly patients treated with dialysis, resuscitation, long-term mechanical ventilation, and nutritional support are shown in table 1. Total utilization ranges from a few thousand persons, in the case of mechanical ventilation, to 1.4 million persons, in the case of nutritional support. Utilization among elderly persons ranges from approximately 2,200 for ventilation to 680,000 for nutritional support. With the exception of the dialysis data, these figures should be regarded as preliminary, probably minimal, indicators of the size of the respective patient groups. The dialysis data are taken from HCFA

Table 1.—Utilization of Life-Sustaining Technologies for Patients of All Ages, and for Elderly Patients, in All Settings Combined

	Total number of patients (all ages)	Patients over 65	
		Number	Percent of total
Dialysis[a]	90,621	27,641	31%
Resuscitation[b]	370,000 to 750,000	204,000 to 413,000	55% est.
Mechanical ventilation	3,775[c] to 6,575[d]	1,250[c] to 2,200[d,e]	34%
Nutritional support[f]	1,404,500	680,000	48% est.
Enteral (tube)	848,100	450,000	53% est.
Parenteral (intravenous)	556,400	230,000	40% est.

[a]1985 HCFA data for Medicare's ESRD program.
[b]Contractor estimates, hospitalized patients only.
[c]1985 data for 37 States, patients dependent on ventilator 14 days or longer.
[d]National estimates extrapolated from survey in Massachusetts.
[e]Elderly defined as over 70.
[f]1984 industry data and contractor estimates.

SOURCE: Office of Technology Assessment, 1987.

records; the other data are based on a combination of industry estimates, published reports, and OTA contractor reports, and were compiled by OTA.

For life-sustaining antibiotic therapy, numerical estimates of utilization are too tentative to report. Although some data exist on the use of antibiotics in general, the number of cases in which treatment is life-sustaining, and the number of patients who are elderly, cannot be estimated.

Differences in data collection methods, definitions, time periods, etc., dictate special caution in comparisons of data for the individual life-sustaining technologies described in this report. (The reader should not conclude from table 1, for example, that 1 in 100 resuscitated patients requires prolonged mechanical ventilation or that 20 times as many people are treated with dialysis as mechanical ventilation.) The figures reported for mechanical ventilation are cross-sectional data; they do not reflect the fact that new morbidity creates a constant stream of patients, i.e., the patients on mechanical ventilation at the time these data were collected might be replaced several times over during the course of a year. The data for dialysis, on the other hand, represent all patients treated during a calendar year.

Also, patients with life-threatening medical conditions may be treated, simultaneously or sequentially, with several life-sustaining technologies. Many ventilator patients require nutritional support, and it has been estimated that 45 percent of all infections acquired in hospitals (*nosocomial* infections) are related to medical devices. Thus, totaling the number of patients receiving each of these life-sustaining technologies would overstate the number of patients receiving *any* life-sustaining technology. In addition, the data in table 1 leave out patients who were treated, but too briefly to appear in the figures (e.g., patients ventilated for less than 14 days).

Future demand for life-sustaining technologies cannot be predicted without accurate information on current utilization and monitoring of changes in use. This problem is vividly illustrated by the brief history of Medicare's ESRD program. Prior to Medicare coverage for dialysis, the number and distribution of dialysis machines and personnel were so limited that treatment was available only to the wealthy and the hand-picked; patients over age 45 were seldom considered. Following enactment of Medicare's ESRD program, the number of dialysis patients of all ages climbed from 5,000 to over 90,000 between 1972 and 1985 (and the number of patients over 65 multiplied by at least a factor of 25)—figures far in excess of the original projections.

Future utilization of life-sustaining medical technologies will be influenced by a number of factors, some of which work in opposite directions. The aging of the population, improvements in the technologies, and availability in new settings will drive increased demand. Although these increases may be great, they are likely to be tempered by cost-containment measures, preventive strategies for specific diseases, changes in procedures and guidelines for treatment decisions, and changes in public attitudes. Increasingly, cries for "death with dignity" and the "right to die" are associated with the rejection of high-technology interventions near the time of death.

FINDING: For resuscitation, mechanical ventilation, dialysis, nutritional support, and life-sustaining antibiotic therapy, persons age 65 and older constitute large proportions of all patients, but small proportions of the total elderly population.

This finding can be stated with confidence despite the numerous caveats about specific numbers. While persons 65 and older constitute about 11 percent of the total U.S. population, they comprise over 30 percent of all patients receiving dialysis, nutritional support, and mechanical ventilation (see table 1). In hospitals, an average of 55 percent of all patients who are resuscitated are elderly. In addition, because elderly persons are known to be at the highest risk for life-threatening infections, it is reasonable to assume that they also comprise a large proportion of individuals receiving life-sustaining antibiotic therapy.

It is important, however, to keep these findings in perspective. While the vast majority of nursing home patients receiving nutritional support are elderly, only 5 percent of all elderly persons are in a nursing home (at any one time), and only a small proportion of nursing home residents (2 to 5 percent) receive nutritional support. The proportion of elderly persons who receive other life-sustaining technologies is much smaller.

FINDING: The costs associated with life-sustaining interventions are uncertain, but certainly high.

In general, available data on the costs of life-sustaining technologies are piecemeal and not comparable. The best data are those compiled by HCFA on the ESRD program. For the other technologies OTA studied, even the concept "cost" has been interpreted inconsistently, depending on *whose* costs are of concern. Thus, some publications that claim to report "costs" actually describe what economists call "charges" (i.e., billed amount) or "expenditures" (i.e., payments). Some reports include in their accounting only the specific services and supplies essential to the life-sustaining technology; others count the total cost of the hospital stay during which a life-sustaining technology is used. There has been no attempt to quantify the full economic impact using a definition of costs that includes factors like lost income of the patient or of family caregivers. What is clear is that the costs to providers, charges to patients, and expenditures by patients and third-parties for life-sustaining technologies *all* are high.

The total cost of care is closely associated with how long the life-sustaining technology is needed. Less obviously, **the costs associated with the initial life-sustaining intervention may be dwarfed by the ongoing costs associated with survival of patients whose health care needs remain great despite or because of the intervention.** This is the case, for example, for severely debilitated people who acquire a life-threatening infection that is effectively treated with antibiotics and who subsequently require an extended stay in a nursing home. Their health and quality of life may remain poor, despite continuing institutionalization and health care.

Another major correlate of cost is the setting in which care is provided. (It must be recognized, of course, that the services, equipment, and expertise available in hospitals v. nursing homes v. the patient's home are not the same.) It is generally assumed that cost (along with charges and expenditures) is highest in the acute care hospital and lowest at home. The movement of high-technology care outside of ICUs and outside of hospitals altogether has been encouraged by, among other things, efforts to reduce health care expenditures. For patients whose needs can be met by a combination of self-care and unpaid family members, with only occasional professional attention, the charges and expenditures for home care are certainly below those associated with hospital care. However, if round-the-clock professional nursing and other attributes of intensive care are needed, it can actually cost patients and payers less to keep the patient in the hospital ICU than to try to "bring the intensive care unit into the home." Similarly, care in a nursing home sometimes costs less than care at home.

Available data on *charges* associated with the use of three life-sustaining technologies in the hospital and in community settings (including home care and other community settings), as reported in published studies and OTA contractor reports, are summarized in table 2. These data show the wide range in charges for one technology versus another, for hospital versus community care, and for different patients within each setting. Daily charges for life-sustaining treatments range from $4 to $500 for different forms of nutritional support. The most expensive of these technologies is mechanical ventilation, with average daily hospital charges of more than $800.

For life-sustaining antibiotic therapy and resuscitation, available data are particularly sketchy. Intravenous antibiotics are estimated to cost $30 to $200 per day, exclusive of the cost of any professional services or institutionalization. For resuscitation, OTA found no reliable cost estimates at all.

Table 2.—Charges for Life-Sustaining Technologies

	Hospital inpatient	Community setting
Dialysis		
Per treatment	—	$68-$200
Per year	—	$20,000-$30,000
Nutritional support		
Enteral		
Per day	$4-$132[a b]	—
Per year	$1,450-$28,200	$3,000-$12,000
Parenteral		
Per day	$25-$500[b]	—
Per year	$9,125-$182,500	$50,000-$100,000
Mechanical ventilation		
Per day	$824[c]	—
Per year	$300,760[c]	$21,235-$216,000

[a]Daily hospital charges for enteral nutrition average $43; for parenteral nutrition the average charge is $196 per day.
[b]Includes formula, equipment and staff time, not hospital stay, 1985 data.
[c]Average charges, including hospital stay, for patients in 37 States, 1985 data.

SOURCE: Office of Technology Assessment, 1987.

Until accurate data are available on the costs and utilization of life-sustaining technologies and until the factors that alter cost and utilization are better understood, health care planning and public policy will be uninformed. Accurate baseline data and projections of demand for life-sustaining treatments are basic to planning of health care facilities, professional training, community resources, technological research and development, and decisions about coverage and reimbursement, including catastrophic health insurance plans. **Better information is also a prerequisite to serious discussion about the need for, or criteria to be used in, rationing of access to health care.**

FINDING: Reimbursement is a major determinant of specific treatment options.

Most of the five technologies OTA studied encompass several treatment options, more than one of which might be suitable for a given patient. For some patients with chronic renal failure, either transplantation or dialysis might be appropriate, and then, more than one method of dialysis might be effective. For some patients who require ventilatory support, either positive pressure or relatively simple, negative pressure devices might be appropriate; similarly, for some patients, nutritional support and antibiotic therapy may be provided effectively by any one of several routes. The availability

Photo credit: Foster Medical Corp.

Some elderly patients make successful adjustment to chronic ventilator dependence. Supportive family members and caregivers are essential.

and level of reimbursement for certain technologies not only influence incentives for treatment v. nontreatment; they also influence the relative utilization of different treatment options. For example, some nutritional support experts believe that higher reimbursement for TPN results in its use for some hospitalized patients for whom tube feeding would be an effective, less expensive option.

The availability and level of reimbursement also determine which settings are available, sometimes encouraging inefficient use of resources or precluding use of the least restrictive environment. Between 1972 and 1982, the reimbursement structure of Medicare's ESRD program encouraged center- and hospital-based dialysis over home care. Medicare coverage for nutritional support of less than 90 days and Medicare coverage for drugs, including intravenous antibiotics, is not available to patients at home. The lack of reimbursement for short-term nutritional support and intravenous antibiotics creates purely financial reasons for continued hospitalization. Similarly, reimbursement for TPN and for mechanical ventilation is sometimes so much more complete for patients who remain in the hospital that **some patients who are well enough to go home cannot afford to do so**. The number of hospitalized elderly (and younger) patients needing life-sustaining technologies who could be safely treated in community settings is unknown.

FINDING: The expansion of life-sustaining technologies to settings other than the acute care hospital has major implications for who and how many will receive treatment.

Currently, the numbers of elderly patients receiving life-sustaining treatments in their own homes, in nursing homes (tube feeding and antibiotics are exceptions), and in other nonhospital settings are relatively small; the overall numbers have been increasing, however, and many observers predict that this trend will continue. If life-sustaining technologies become widely available in nursing homes and patients' homes, they may be offered more readily, to more patients and different kinds of patients, and they may also be more readily accepted by patients who now would refuse them. Some observers warn that increased availability of life-sustaining technologies in nonhospital settings, especially if it is accompanied by increased reimbursement, could lead to serious overuse.

In general, patients who can be cared for in their own home enjoy benefits that contribute to their quality of life. In contrast to patients in the more restrictive and strange environments of hospitals and their ICUs, some chronic ventilator patients, home dialysis patients, and home nutritional support patients retain a certain amount of independence, despite physical dependence on technology. Even for patients whose functional ability is severely limited, care in their own home allows them to maintain considerable control over their health care and other aspects of their life, including social relationships.

The number of elderly persons who can be maintained on life-sustaining technologies in their own homes is limited. Complex home care

requires, at a minimum, a patient who is medically stable and cooperative, capable and dedicated family members or companions, a suitable physical environment, support services in the community, and adequate reimbursement or personal financial resources. These conditions, difficult for patients of any age to meet, probably preclude most elderly patients. For mechanical ventilation, about 34 percent of patients of all ages, but only 14 percent of elderly patients are cared for in their own homes. It must be recognized, however, that the feasibility of home care for elderly patients varies with the technology that is needed. For TPN, 20 percent of home care patients are elderly. And, for tube feeding, it is estimated that as many as 55 percent of all home care patients are elderly.

There are numerous impediments to the optimal distribution of patients across settings. Some patients who could be safely transferred to nonhospital settings remain in hospitals, often indefinitely, because caregivers are not available for home care or because of a lack of services and facilities within their community. There is a scarcity of nursing home beds for technology-dependent patients because few nursing homes have adequate staff (or adequate incentives to develop staff) to provide the level of care these patients require. Some physicians and institutions remain unaware or unconvinced about the home care option and do not present it to patients. Some patients who have been discharged home have been forced to return to the hospital because of superior reimbursement in that setting. Information and service networks need to be developed to help ensure that all settings that are medically safe receive consideration.

FINDING: For many patients, life-sustaining treatment in the acute care setting creates the need for chronic care and continuing technological support.

Because life-sustaining technologies seldom cure the underlying condition or restore normal physiological functioning, some patients who survive an acute intervention require continuing treatment for the rest of their lives. Acute dialysis or acute ventilation may evolve into prolonged, chronic, or permanent need for these technologies, with or without potential for rehabilitation. Chronic dependence on a life-sustaining technology is accompanied by continuous need for services or facilities that are typically both expensive and scarce.

Individuals who must remain institutionalized occupy a bed in the ICU, hospital, or nursing home, utilizing facilities, personnel, equipment, and other resources for which other patients may be competing. Individuals who are able to return to the community have needs that include reliable sources for medical equipment and supplies, professional and nonprofessional caregivers (including family members and other assistants), and maintenance and repair of equipment. One aspect of this continuing need is the high, and ongoing, cost of care. Another crucial aspect is that the necessary services and the linkages to coordinate them are unavailable in many communities.

A patient's need for long-term technological support is often difficult to predict, but this possibility must be recognized when the initial decision to provide acute care is made. Some argue that it is unethical to provide health care to acutely ill patients if society lacks the commitment also to provide chronic health care and related services—especially if those needs were created by the acute intervention. The discontinuity in existing health care services leaves some technology-dependent patients and their families in a predicament that they did not foresee when faced with the initial treatment decision.

Coordinated systems of care for technology-dependent persons exist in some European countries, and these models may be instructive. In France and in England, for example, systems are in place to provide comprehensive services that enable chronic ventilator patients to remain in their communities. These are regional programs that provide services ranging from group purchasing of medical supplies to equipment repair, patient education, and emergency care. In existence for more than 20 years, these systems are said to be economical and to improve the quality of life for these patients.

Quality of Care

FINDING: There are some questions about the quality of care related to the use of life-sustaining technologies, particularly for elderly patients.

Although OTA did not specifically seek information related to the quality of care, some issues emerged. Perhaps most important, **there is ample evidence that some treatment options or procedures should be tailored to age, but there is little evidence that they are.** Despite the fact that age-related changes in the metabolism of drugs are now well recognized, for most antibiotics, dose and dose interval remain standard regardless of the patient's age. Similarly, although it is well established that nutritional requirements change with age, the details are not well understood, and nutritional formulas are frequently not adjusted to these changes, especially for patients on tube feeding. For the other life-sustaining technologies OTA studied, the possibility that the clinical outcomes for elderly patients might be improved if modifications were made either in the equipment or procedures has barely been addressed. Modifications in these treatments to account for age-related differences depend on continuing basic research in gerontology and other fields and on dissemination of this knowledge through professional training.

The traditional bias of medical education and practice places the cure of acute illness above all other goals. When cure is not a realistic goal, this approach often leads to inappropriate treatment decisions. Recent changes in the curricula of many health professions recognize this problem and seek to improve care by acknowledging and focusing on achievable goals, such as maximization of the patient's functional capacity and the quality

of life. Pertinent curricular innovations include new courses in geriatrics, medical ethics, humanities, and death and dying.

Other quality of care issues result from shifts in the settings in which life-sustaining technologies are applied and changes in the personnel who are responsible for care. In nonhospital settings, responsibility for patient care is often entrusted to less trained professionals and to laypersons. The education and supervision of patients providing self-care, family members, and other lay caregivers, as well as home health care professionals are important issues. Health care personnel trained in the use of complex technologies have typically not been trained to work in community settings or to work with elderly persons. Maintenance and repair of equipment and availability of backup equipment can also be problems when life-sustaining technologies are used outside the hospital.

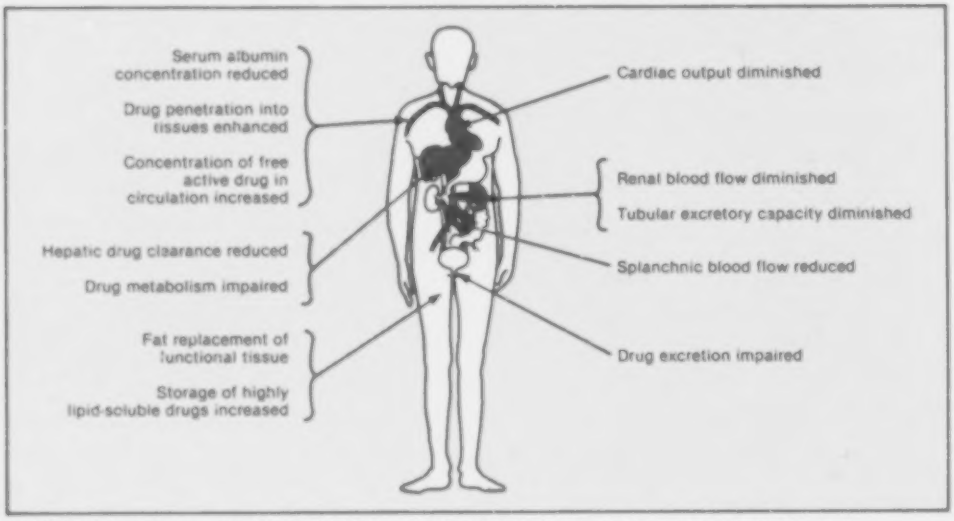
A different kind of quality of care issue concerns the technological hardware for certain life-sustaining technologies; this includes the primary medical device as well as the various peripheral supplies and components (e.g., tubing, solutions, power sources). Questions have been raised about the quality, safety, and suitability of some enteral formulas for nutritional support. Also, the Food and Drug Administration (FDA) has received a large number of reports of mechanical ventilators that have malfunctioned or failed. In some cases, only voluntary standards apply to the manufacture of devices and products used to sustain life.

FINDING: Technological developments have improved the safety and efficacy of life-sustaining technologies, as well as the quality of life for some patients who are dependent on them.

Research and development (R&D) in many arenas, including physiology, medicine, engineering, electronics, biofeedback, and computer science, have brought continuous change in existing life-sustaining technologies as well as completely new technologies to sustain life (see app. C). Stimulated by competition for health care markets, perceived need to improve available products, regulatory standards, etc., R&D within the public and private sectors has resulted in more and better devices and methods for diagnosing, monitoring, and treating severely ill patients in both traditional and nontraditional settings.

General technological advances (e.g., miniaturization, computerization, new materials, and automation) have made possible improved efficacy, safety, and reliability of many medical devices. One example is the development of automatic blood gas analyzers, considered a watershed in mechanical ventilation technology. Other kinds of technological developments have meant improved comfort and independence for some patients. Innovations that reduce the size and weight of equipment, extend time between treatments, reduce the need for professional services, or make home care possible enhance the quality of life for many patients. Improved blood access systems for hemodialysis are a good example. Prior to development of the Teflon shunt in 1960, patients had to undergo the inconvenience, discom-

Figure 2.—Factors Affecting Drug Distribution in the Elderly


Serum albumin concentration reduced
Drug penetration into tissues enhanced
Concentration of free active drug in circulation increased
Hepatic drug clearance reduced
Drug metabolism impaired
Fat replacement of functional tissue
Storage of highly lipid-soluble drugs increased
Cardiac output diminished
Renal blood flow diminished
Tubular excretory capacity diminished
Splanchnic blood flow reduced
Drug excretion impaired

SOURCE: Adapted from I.M. Smith, "Infections in the Elderly," *Hospital Practice*, 17(7):69-85, 1982.

fort, and risk of infection associated with having a new surgical procedure for every dialysis treatment.

A potential benefit of continuing R&D is cost reduction. New methods of manufacture, new materials, and new markets may lower the production cost of certain equipment and supplies. If lowered production costs are reflected in prices or in reimbursement, this would result in lower treatment costs for some patients. Existing incentives to develop medical technologies that are less expensive and incentives to substitute lower for higher cost technologies appear largely tied to interest in the home health care market.

Access to Care

FINDING: When resources are available, patients with life-threatening conditions are more likely than not to receive aggressive treatment.

The acute care orientation in medical training and practice emphasizes cure and prolongation of life and justifies "doing everything humanly possible" to achieve these goals. This *bias to treat* appears to prevail for patients of all ages. It has been reinforced by the wide availability of life-sustaining technologies in hospitals, reluctance to consider cost as an appropriate factor in individual decisionmaking, health professionals' and institutions' fear of legal action, and the weighty uncertainties surrounding treatment decisions. Since a wrong decision is irreversible, most health professionals would choose to "err on the side of life."

While withholding of treatment is resisted, withdrawal may be even more so. Despite wide agreement among ethicists and legal scholars that there is no theoretical basis for distinguishing between withholding and with-

drawal of life-sustaining technologies, **in actual practice it is frequently *easier* to withhold a life-sustaining treatment whose benefit is uncertain than later to "pull the plug," even when the patient or patient's surrogate requests this.** Grief, guilt, and health professionals' feelings of failure at times prevent rational decisionmaking.

Some health professionals and family members view withdrawal of aggressive medical treatment as "giving up" or even "abandonment" of the patient. On the other hand, some believe there is a greater moral imperative to withdraw treatment that proves to be futile or unwanted than to initiate an intervention that is of uncertain value. This position emphasizes the need for continual reevaluation of the medical indications for treatment. Some persons who hold this view advocate the use of *time-limited trials*. For example, mechanical ventilation could be instituted with the provision that its use be reconsidered after 1 week; dialysis could be tried for 4 months, etc. After a designated trial period, the patient's situation could be thoroughly evaluated; there would be an opportunity to assess the value of treatment and to ascertain the patient's wishes.

In addition to philosophical and psychological difficulties, practical difficulties at times discourage the withdrawal of life-sustaining technologies. To withdraw most life-sustaining treatments requires a specific physician order, frank and time-consuming conversations with the patient and/or family, conferences among members of the health care team, and formal documentation in the patient's record. At times, institutional review committees, ethics committees, legal advisers, or the courts become involved in decisions to withdraw treatment. While decisionmaking procedures vary with the technology being considered, the decision to withhold treatment is generally less explicit than the decision to withdraw it.

FINDING: Relative access to life-sustaining technologies by different segments of the population cannot be assessed with available data.

Health professionals' preference to provide rather than to withhold treatment and to withhold rather than withdraw it are competing biases whose impact on access to life-sustaining treatments is not clear. Many other factors, notably reimbursement, also influence accessibility of health care and determine whether or not various segments of the population have equal access. Between 1965 and 1983, Medicare's cost-based reimbursement system facilitated the development and diffusion of medical technologies in general, and made life-sustaining technologies available to hospitalized elderly patients with little regard to cost. It is not yet clear what impact Medicare's prospective payment system for hospital care has had on accessibility of life-sustaining treatments. Available utilization data prove that elderly persons have *considerable* access to life-sustaining treatments, but utilization data alone do not permit conclusions about whether access is restricted (leading to undertreatment) or excessive (leading to overtreatment).

Public opinion and concerns expressed by health professionals suggest that overtreatment—i.e., provision of treatment that is or becomes unwanted

or unbeneficial—is more frequent than undertreatment. In 1985 the National Institutes of Health cosponsored a conference on Withholding and Withdrawing Mechanical Ventilation in response to wide agreement among clinicians that the technology is too often started and too often continued inappropriately. It should be noted, however, that because treatment is easier to count than nontreatment, overuse is probably more visible than underuse.

Cost-containment pressures in general and Medicare's prospective hospital payment system in particular force health care decisionmakers to acknowledge that resources are limited and that all patients cannot have "everything possible." The pressure to reduce costs has spawned legitimate concerns among health professionals and the public that every patient will not have everything that is *desirable*. In the absence of guidelines for how costs are to be reduced, it is unclear which patients will be affected the most. Since Medicare is a program for elderly citizens, however, the patients most directly affected by hospitals' and physicians' efforts to reduce health care costs under Medicare are those over 65.

It appears that questions about equality of access should not just make the usual comparisons of rich and poor, old and young, or black and white. Pertinent concerns also include setting, cognitive ability, and age subgroup. Anecdotal evidence and small studies suggest that a nursing home resident with a life-threatening infection is less likely to be treated than if that same person were in an acute care hospital; persons with severely impaired cognitive ability—whose quality of life is perceived to be poor and who cannot speak for themselves—are also less likely to receive aggressive treatment; relatively young elderly persons and those who have a spouse are more likely to be treated than those who are older or alone.

Since 1983, evidence of changes in hospital admission policies and the continued reduction in length of stay suggest that limited Medicare payment may have begun to influence treatment options that are made available. Some Medicare patients whose treatment costs are expected to exceed payment for their diagnosis-related group (DRG) have been dubbed "DRG losers," and there is mounting anecdotal evidence that some persons have been denied admission to certain hospitals or denied admission to the ICU.[3] **Despite financial incentives to limit expensive care, however, there is no evidence to date that PPS has reduced access to *life-sustaining* treatment.**

As cost-containment measures are implemented in Medicaid and in private health insurance programs, patients of all ages are more likely to receive reduced care. It remains to be seen whether savings are or will be found by cutting services to all patients or by cutting services to particular groups of patients. There is wide agreement that, under PPS, Medicare patients are being discharged from hospitals "quicker and sicker." At the same time, however, Medicare patients who are retained in hospitals are also sicker *and older* than before PPS. The meaning of these findings and the

[3]A study in one hospital found that Medicare patients in specified circulatory system DRGs, who were treated in the ICU, resulted in losses to the hospital ranging from $674 to over $24,000 per discharge. Such dramatic effects have attracted considerable attention among health professionals and institutions.

extent to which they are caused by PPS is a subject of considerable debate that is outside the scope of this assessment.

FINDING: For patients who do not want life-sustaining technologies and patients for whom these technologies are not medically indicated, treatment options have been relatively unexplored and are not widely available.

Treatments whose goal is to control pain and suffering, even at the risk of hastening death, are regarded by many people as reasonable alternatives to aggressive life-sustaining medical treatment. There is anecdotal evidence, however, that patients who refuse life-sustaining treatment that is offered and patients from whom aggressive treatment has been withheld or withdrawn are sometimes neglected by health professionals. Persons capable of providing alternate forms of treatment—especially hospice care and palliative or supportive care—may not be available. Also there are legal and ethical uncertainties regarding when and how it may be appropriate to limit treatment. Medicare reimbursement for hospice care is currently available only in special circumstances, only to patients who have been diagnosed as "terminally ill" and then, of course, only where hospice facilities and/or personnel are available.

Decisionmaking Problems and Processes

FINDING: Decisions about the use of life-sustaining technologies are made amid great uncertainty regarding the likely clinical outcomes.

Decisions about whether or not to institute life-sustaining treatments would be relatively easy if it were known in advance whether or not the patient would survive, for how long, and in what condition. But, variations in patients' physiological and psychological adjustment, and in the quality of care they receive, make highly uncertain the outcomes of any treatment for any given patient. Pervasive *prognostic uncertainty* means it is impossible to predict whether or not any treatment will be effective, whether a particular treatment is optimal, or whether a patient would survive without treatment.

The inability to prospectively identify patients who will benefit from treatment arises because, contrary to popular belief, **life-sustaining technologies are frequently ineffective. For acutely ill patients of all ages, aggressive treatment is associated with high mortality and serious complications.** At best, one-third to one-half of all in-hospital resuscitation attempts succeed; and only one-half of the patients who are successfully resuscitated survive long enough to be discharged from the hospital. In acute episodes of respiratory failure, adults treated with mechanical ventilation have about a 50-percent chance of surviving; for acute renal failure, only 20 percent of persons over age 70 survive. Patients receiving antibiotic therapy or nutritional support have a relatively high, but not necessarily predictable, chance of survival.

Photo credit: Gretchen Kolsrud

The lives of some severely debilitated nursing home residents can be sustained for prolonged periods by nasogastric tube feeding.

Prognosis is often especially difficult when the patient is elderly. The interaction of disease (especially multiple coexisting diseases) with reduced physiological reserve makes diagnosis in elderly patients difficult and responses to treatment particularly difficult to predict. The clinical uncertainties may be exacerbated by the shortage of basic scientific knowledge about aging and the shortage of personnel trained in geriatric assessment and care.

Inability to accurately predict the outcomes of particular treatments can result in two kinds of errors—i.e., treatment of patients for whom treatment is futile and failure to treat patients who would survive. Reducing both kinds of errors would not only avoid useless suffering for patients and families, but is tantamount to more rational and efficient use of health care resources. Studies of the outcomes of critical care have shown that the cases in which costs are highest are those in which the outcome was inaccurately predicted.

Basic and clinical research are among the necessary approaches to reducing clinical uncertainty and, thereby, to improving the content of treatment decisions. Information is needed about the physiological and psychological responses of elderly patients to particular treatments as well as information about the outcomes *without* treatment. Dissemination of this information through education and training of health care professionals would strengthen their ability to evaluate, and to help patients understand, the relative risks and benefits of treatment options.

Research is underway on a variety of methods to combine diagnostic and treatment data into statistical categories that are associated with known probabilities of survival. Theoretically, reliable classification systems could provide physicians an improved basis for predicting the outcome of treatment. An OTA workshop on such systems of patient classification, held in conjunction with this assessment, concluded that, although the current state-of-the-art is limited and systems remain experimental, there is reason to believe that refined patient classification systems will effectively reduce clinical uncertainty and provide valuable help in making some kinds of treatment decisions.

FINDING: For an individual patient, chronological age is a poor predictor of the outcome of treatment with life-sustaining technologies.

The statistical odds of survival are worse for elderly than for younger adults who receive a life-sustaining intervention, but neither age 65—nor any single age criterion—is an adequate predictor of physiological or psychological response to treatment. Moreover, because physiological and psychological diversity increase as people age, response to particular technological interventions may be *hardest* to predict in the oldest patients.

Available data for most of the life-sustaining technologies OTA studied substantiate that elderly patients, as a group, have lower survival rates and more complications. With dialysis, for example, the mortality rate among elderly patients is three times as high as that for all patients (45 v. 15 per-

cent). On the other hand, elderly patients, on the whole, seem to make a better psychological adjustment to chronic dialysis than do younger patients. Generalizations based on the patient's age, while they may be statistically accurate, obscure the fact that many individual elderly patients survive and thrive after treatment with a life-sustaining technology.

For patients of all ages, life-sustaining technologies are associated with numerous potentially serious complications. It has sometimes been assumed that elderly persons, as a group, are at higher risk of such complications and that the complications elderly patients experience are apt to be more serious. In fact, data to support this assumption are inconclusive and vary with the technology. For example, while increased risk of rib fractures is frequently mentioned in connection with resuscitation of elderly persons, OTA is unaware of data to support this. Moreover, any statistical association between age and rib fractures is due not to age per se, but to age-related diseases that make the bones brittle (e.g., osteoporosis).

To some degree, the worse outcomes of elderly patients may stem from inadequate expertise regarding aging and geriatric care. Health professionals' inattention to or misinterpretation of pertinent clinical information can lead to unwarranted generalizations about elderly patients and to a self-fulfilling prophecy. If it is reasoned, for instance, that an elderly person should not receive aggressive life-sustaining treatment "because he won't do well," he is almost certain to not do well!

Most of the patient classification systems OTA reviewed include chronological age as one variable in the statistical prediction model. Even in these abstract mathematical models, **age contributes less to the prediction than other patient characteristics, including severity of illness, diagnosis, or previous health status.** So great is individual variability that some researchers and clinicians argue that the patient's age should be disregarded in making treatment decisions. Others advocate development of a proxy for age that more accurately reflects the health status and reserve capacity of individual patients.

FINDING: The legal and ethical uncertainties that surround decisions about the use of life-sustaining technologies have led to intense interest in the development of decisionmaking supports and guidelines.

Profound ethical uncertainties in decisions about life-sustaining technologies emanate from the plurality of cultural and religious orientations that characterize this society and that affect people's values and beliefs about such fundamental things as the meaning of life and the meaning of death, individual v. public good, and the quantity v. quality of life. Ethical quandaries may make it difficult to discern the goal of the decision (e.g., patient autonomy v. survival, etc.), the means to achieve it, or both.

Grave legal uncertainties arise because there are situations in which no pertinent legislation exists, because legislation differs in different jurisdictions, and because the law is changing. Legal precedent and case law offer

Figure 3.—Utah's Form for Creating a Living Will

This directive is made this _____day of _____, 19___:

1. I, _____, being of sound mind, willfully and voluntarily make known my desire that my life not be artificially prolonged by life-sustaining procedures except as I may otherwise provide in this directive.
2. I declare that if at any time I should have an injury, disease, or illness, which is certified in writing to be a terminal condition by two physicians who have personally examined me, and in the opinion of those physicians the application of life-sustaining procedures would serve only to unnaturally prolong the moment of my death and to unnaturally postpone or prolong the dying process, I direct that these procedures be withheld or withdrawn and my death be permitted to occur naturally.
3. I expressly intend this directive to be a final expression of my legal right to refuse medical or surgical treatment and to accept the consequences from this refusal which shall remain in effect notwithstanding my future inability to give current medical directions to treating physicians and other providers of medical services.
4. I understand that the term "*life-sustaining procedure*" does not include the administration of medication or sustenance, or the performance of any medical procedure deemed necessary to provide comfort care, or to alleviate pain, except to the extent I specify below that any of these procedures be considered life-sustaining.
5. I reserve the right to give current medical directions to physicians and other providers of medical services so long as I am able, even though these directions may conflict with the above written directive that life-sustaining procedures be withheld or withdrawn.
6. I understand the full import of this directive and declare that I am emotionally and mentally competent to make this directive.

Declarant's Signature

City, County and State of Residence

We witnesses certify that each of us is 18 years of age or older and each personally witnessed the declarant sign or direct the signing of this directive; that we are acquainted with declarant and believe him to be of sound mind; that the declarant's desires are as expressed above; that neither of us is a person who signed the above directive on behalf of the declarant; that we are not related to the declarant by blood or marriage nor are we entitled to any portion of declarant's estate according to the laws of intestate succession of this state or under any will or codicil of declarant; that we are not directly financially responsible for declarant's medical care; and that we are not agents of any health care facility in which the declarant may be a patient at the time of signing this directive.

Signature of Witness	Signature of Witness
Address of Witness	Address of Witness

SOURCE: Utah Personal Choice and Living Will Act, Code No. 75-2-1101, 1985

valuable, but not always consistent, guidance. Uncertainty about what actions are legal fuel health professionals' widespread fear of the law, and fear of malpractice litigation is an important factor in clinical decisionmaking. Some of this fear is well founded; some, however, results from health professionals' ignorance or misinterpretation of the law.[4]

[4]See M.B. Kapp and B. Lo, "Legal Perceptions and Medical Decisionmaking," prepared for the Office of Technology Assessment, U.S. Congress, Washington, DC. March 1986. Available from the National Technical Information Service, Springfield, VA.

Decisionmaking problems are made still more complex by the fact that, in most cases, there is not one decision to be made (e.g., whether or not to start dialysis), but rather a series of decisions (e.g., whether to hospitalize, to do a particular diagnostic test, to put the patient in the ICU, to continue treatment, etc.). And, separate from the questions about what the decision should be are serious questions about how the decision should be reached. If, for example, the patient disagrees with medical advice, what should be done? If the patient is not decisionally capable, who shall be the surrogate? The variety in patients' physical status, decisionmaking capacity, severity of illness (emergency or not), social circumstances (especially whether one is in the community or in an institution), and family situation (especially whether or not there is a designated surrogate) mean that no single approach to decisionmaking can be applied in all instances. These difficulties have stimulated legislative, institutional, and professional responses.

Possible roles of government in reducing the uncertainties surrounding decisions about life-sustaining technologies include Federal or State legislation and regulations and support for research. To date, the legal response has been primarily the enactment of new laws at the State level. Living will laws have been enacted in 38 States and the District of Columbia. All States and the District of Columbia have durable power of attorney statutes, and 15 States have statutes that specifically authorize the use of a durable power of attorney for health care decisionmaking. These advance directives protect the rights of patients to participate in health care decisions even after they become decisionally incapable and, by clarifying the patient's treatment preferences, offer health care providers a measure of protection as well. Family consent laws, that specify the right of family members to make treatment decisions for an incompetent person, are another option. In some States, courts have mandated specific procedures that must be followed in decisionmaking about life-sustaining technologies. Each form of legal response does a partial job of solving the problems that arise in decisions about life-sustaining treatment. The clinical and ethical dilemmas, of course, remain.

As recommended by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, some health care institutions, especially hospitals, have developed policies or guidelines that specify how decisions about life-sustaining technologies will be made. These attempt to ensure quality of care and to reduce risk to the institution and its staff. Always, institutional policies are subservient to existing State laws and mandates (or, in the case of some Federal institutions, Federal law) regarding advance directives, family consent, malpractice, etc. **In almost all cases, institutional policies are procedural, not substantive. That is, they emphasize how a decision should be reached, not what it should be.**

Acute care hospitals are the institutions most likely to have policies regarding decisions about life-sustaining technologies.[5] The hospital policies

[5]A 1986 survey by the Joint Commission on the Accreditation of Hospitals found that 57 percent of acute care hospitals, 43 percent of hospices, and 20 percent of nursing homes have formal policies for decisions about resuscitaiton.

OTA has reviewed tend to be very cautious and to presume that treatment will be provided. Most focus on clinical criteria for particular treatments, especially resuscitation, and specify procedures for designating and implementing Do-Not-Resuscitate (DNR) orders. Some institutional policies specify alternate levels of care and then have a procedure for assigning patients to each level. Under this kind of policy, patients may be designated, for example, "do not resuscitate," "do not intubate," or "supportive care only."

Institutional policies make explicit the presumption for or against treatment in a facility, who will be involved in a treatment decision (patient, family, attending physician, other physicians, nurses, ethics committee, other facility staff), and how advance directives will be regarded. Institutional guidelines may address ways to protect patient autonomy, for patients who are decisionally capable and those who are not, and ways to resolve conflicts.

There is now some movement toward requiring policies as a standard for accreditation of institutions. In June 1987, the Joint Commission on the Accreditation of Hospitals (JCAH) adopted a standard requiring hospitals and nursing homes to have a policy for decisions about resuscitation by 1988.

Ethical analysis is increasingly recognized as a useful tool in making treatment decisions. Thus, another institutional response has been the establishment of institutional ethics committees or employment of a philosopher or theologian to assist in the resolution of troublesome cases. At least half of all acute care hospitals, and higher proportions of large hospitals and teaching hospitals, have established ethics committees to assist in decisionmaking for difficult cases. A few nursing homes have also established institutional ethics committees. Typically, these committees include physicians, nurses, administrators, attorneys, social workers, and lay persons who review specific cases brought to their attention. Individual institutional policies specify the role of these parties in the decisionmaking process. In most instances, decisions made by ethics committees are regarded as advisory.

Associations of health care professionals have shown strong interest in developing decisionmaking guidelines themselves, partly in an effort to avoid government intervention. Some of these are clinical guidelines, specifying when a particular treatment is medically indicated. Some, notably the American Medical Association's (AMA) 1986 statement on "Withholding or Withdrawing Life Prolonging Medical Treatment," address the physicians' legal and ethical responsibilities in making these decisions. The AMA statement specifies that "life prolonging medical treatment," which "includes medication and artificially or technologically supplied respiration, nutrition or hydration" may be withheld or withdrawn when doing so is in the patient's best interest.

Another example of the interest in guidelines is the list of "principles for decisionmaking" developed by the advisory panel to this OTA assessment (see box A). These express the strong convergence of opinion—but not unanimity—of a panel of physicians, nurses, lawyers, ethicists, and economists regarding many of the fundamental questions.

Box A.—Principles for Decisionmaking Regarding the Use of Life-Sustaining Technologies for Elderly Persons, as Developed by OTA's Advisory Panel

NOTE: *Members of the Advisory Panel to this OTA assessment (see title page) sought to express their strong convergence of opinion regarding many of the fundamental questions regarding the use of life-sustaining technologies for elderly persons. The following list of principles for decisionmaking was developed at the final meeting of the Panel, in February 1986. These are the personal views of the majority of Panel members, all of whom were present at the meeting or subsequently polled. It should be noted that dissent, while rare, was in some cases strong. These principles do not necessarily reflect the opinion of OTA, staff for this assessment, members of the Technology Assessment Board, or members of the assessment's requesting committees. With these caveats, the following principles are offered to Congress and the public for consideration.*

- An adult patient who is capable of making decisions has the right to decline any form of medical treatment or intervention. However, an individual does not necessarily have a right to unlimited medical treatment or intervention.
- Decisions regarding the use of life-sustaining treatments must be made on an individual basis and should never be based on chronological age alone. Chronological age per se is a poor criterion on which to base individual medical decisions; however, age may be a legitimate modifier regarding appropriate utilization of life-sustaining medical technologies.
- Diagnosis alone is a poor criterion for decisions about the use of life-sustaining technologies. Because of the great variability among patients with the same diagnosis, patient assessment must also include measures of functional impairment and severity of illness.
- Cognitive function is an important marker of the quality of life.
- The courts are not and should not be the usual route or determinant for making decisions about the use of life-sustaining technologies or for resolving the dilemmas these technologies may create.
- There is little need or room for Federal legislation concerning the initiation, withholding, or withdrawal of specific life-sustaining technologies.
- There is a major need for a clear, workable definition of the appropriate role of surrogates in health care decisionmaking, including the nature of their responsibilities and their suitability to make decisions.
- There is a need to recognize that a process exists, or should exist, for making decisions about the use of life-sustaining technologies. The process described by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research could serve as a model.
- A physician or other health professional who does not want to follow the wishes of a patient who is capable of making decisions regarding his or her treatment should withdraw from that case.
- Socioeconomic status should not be a barrier to access to health care, including life-sustaining interventions.
- There is an important need for education of the public and health care

providers regarding the nature and appropriate use of life-sustaining technologies.

- There is a specific need for improved clinical information that would predict the probability of a critically or seriously ill patient's survival, functional status, and subsequent quality of life.
- There is a wide range of medical and legal disagreement and varying levels of emotional strain and moral conflict about the appropriate use of life-sustaining technologies. The great heterogeneity of the American population makes consensus difficult and increases the likelihood of formal institutional decisionmaking procedures.

FINDING: In practice, many patients are not involved in decisions about the use of life-sustaining technologies.

The patient's involvement in decisions about the use of life-sustaining technologies varies widely depending on the urgency of the medical event, the setting, the patient's cognitive status, and established decisionmaking procedures. For the technologies OTA studied, the patient's consent to treatment is frequently not obtained, and even when consent is obtained, it is frequently not "informed."

Sometimes the patient is left out of the decisionmaking process because the need for immediate action or the patient's mental state makes it impossible to do otherwise. Victims of cardiac or respiratory arrest, for example, are typically unconscious or in a severely compromised mental state; moreover, the imminent risk of brain damage does not permit time for discussion with other persons who may know the patient's wishes. In such emergencies, when the patient's consent for initiation of treatment is unobtainable, consent is usually "implied." Thus, emergency medical technicians responding to calls are usually obligated to try to resuscitate every victim of cardiac arrest, not to pause and ask whether this is wanted.

In the case of resuscitation, the bias to treat is so strong that the normal presumption about informed consent is reversed. That is, patients (or their surrogates) are likely to be consulted if a DNR order is being considered, but unlikely to be consulted for consent *to resuscitate*.

Cognitive impairment resulting from dementia or depression is another major factor in patients' involvement in treatment decisions. Patients who, based on formal or informal assessment, are considered to have severely impaired cognition are commonly excluded from decisions about their care. Some of these people, however, if given the opportunity, express consistent wishes regarding treatment v. nontreatment. Since the prevalence of dementia increases with advanced age, elderly patients as a group are less likely than younger adults to be able to actively participate in decisions about their care.

If a patient is determined decisionally incapable, a surrogate decisionmaker can be, and frequently is, designated. This may be done informally, as when the physician turns to the patient's spouse or an adult child. Or a surrogate may be formally appointed, by the patient or by a court. Some States specify a hierarchy of family members who have decisionmaking

Figure 4.—Sample of a General Form for Creating a Durable Power of Attorney for Health Care

I, _____, hereby appoint: _____
name/address

as my agent to make health care decisions for me if and when I am unable to make my own health care decisions. This gives my agent the power to consent to giving, withholding or stopping any health care, treatment, service, or diagnostic procedure. My agent also has the authority to talk with health care personnel, get information, and sign forms necessary to carry out those decisions.

If the person named as my agent is not available or is unable to act as my agent, then I appoint the following person(s) to serve in the order listed below:

1. _____ 2. _____
name address name address

By this document I intend to create a power of attorney for health care which shall take effect upon my incapacity to make my own health care decisions and shall continue during that incapacity.

My agent shall make health care decisions as I direct below or as I make known to him or her in some other way.
(a) Statement of Desires Concerning Life-Prolonging Care, Treatment Services and Procedures:

(b) Special Provisions and Limitations:

By signing here I indicate that I understand the purpose and effect of this document.

I sign my name on this form on _____

My current home address _____
(You sign here)

Witnesses:

I declare that the persons who signed or acknowledged this document is personally known to me, that he/she signed or acknowledged this durable power of attorney in my presence, and that he/she appears to be of sound mind and under no duress, fraud, or undue influence. I am not the person appointed as agent by this document, nor am I the patient's health care provider, or an employee of the patient's health care provider.

First Witness: _____ Second Witness: _____
name/address name/address

(At least one of the above witnesses must also sign the following declaration.)

I further declare that I am not related to the patient by blood, marriage, or adoption, and to the best of my knowledge, I am not entitled to any part of his/her estate under a will now existing or by operation of law.

_____
name address

SOURCE: Barbara Mishkin, Hogan & Hartson, Washington, DC.

authority if a surrogate is needed; others have a "durable power of attorney for health care" statute.

In some cases, it is possible to obtain the patient's informed consent, but the treatment in question is considered so "ordinary" that standard prac-

tice diverges from the law requiring informed consent. Antibiotic therapy, especially in the hospital setting, is so routine that health professionals often consider consent unnecessary, and they do not seek it. Also, health professionals' perceptions of some interventions as ordinary or noninvasive mean that, **in practice, different treatment modalities for a single life-sustaining technology can involve different decisionmaking practices.** Thus, in many institutions, a nasogastric tube may be placed for the provision of enteral nutrition without the patient's consent—even though formal consent is always required for surgical placement of a gastrostomy tube for enteral nutrition or a catheter for TPN.

Many patients, particularly elderly patients, are accustomed to a passive role in the doctor-patient relationship and to accepting the advice of trusted health professionals without questioning. Persons who have developed this behavior over a lifetime cannot be expected to start seeking information or to take an active role in treatment decisions when those decisions are most difficult. A 1982 national survey reported that 38 percent of respondents of all ages, and 60 percent of elderly respondents, "want the responsibility of making the final choices about your medical treatment" to rest with their doctor. Some elderly persons prefer to entrust important treatment decisions to their spouse or an adult child.

The urgency of many life-threatening conditions and the fact that patients may be decisionally incapable at the time a treatment decision must be made point to the importance of determining patients' wishes about life-sustaining treatments *before a life-threatening emergency occurs*. Implementation of the patient's wishes is frequently dependent on advance planning. This may take several forms, including: discussions with family members and/or health professionals about treatment options, with documentation in the medical record or in a formal advance directive, such as a "living will"; designation of a surrogate decisionmaker; or institutional policies that ask patients to indicate their treatment choices upon admission.

Many health professionals believe that the goal of truly informed consent is often illusory even when there is time for discussion and the patient is fully in command of his or her cognitive faculties. In addition to the difficulty most laypersons would have in understanding the details of their condition and the treatment options, the gulf between hypothetical and actual situations is wide. It is unlikely, for example, that a layperson (or a health professional) who has not personally experienced mechanical ventilation can fully comprehend the impact of this treatment. By the same token, it is impossible to anticipate what it is like to be unable to breathe. Physicians' observe that many people "change their mind [about being intubated for mechanical ventilation] when they are choking to death," and this observation contributes to their skepticism about advance directives.

Even when the patient has been informed about treatment options and his or her wishes have been specified, problems remain in ensuring that these wishes are implemented, especially if they call for limited treatment. Neither an advance directive nor the instructions of a surrogate can be followed if authorities do not know one exists or if the document

or person cannot be located. Advance directives that indicate refusal of life-sustaining treatment are sometimes overruled because they are considered "too vague." This can happen if, for example, the patient's circumstances or the treatment being considered was not anticipated when the directive was written, and physicians think treatment will be beneficial. Inconsistencies in State laws are a major problem. Some States will not recognize an advance directive that was made in another State. In many States, advance directives do not become operative until or unless the patient is diagnosed "terminally ill." Moreover, some State living will statutes include provisions that, in the view of some people, contradict the common law right to refuse treatment, by specifying, for instance, that nutritional support must always be provided. A patient preference that runs counter to the advice of health professionals is often interpreted as "irrational," and efforts will be made to change the patient's mind or to circumvent the patient's request. In such cases, the patient's decisionmaking capability may be called into question, and efforts made to appoint a surrogate or a guardian. In general, consent to recommended treatment is easier to implement than is refusal of recommended treatment, and any patient wish is easier to carry out if it is consistent with the advice of caregivers and the wishes of family members.

Finally, **decisions about the use of certain noninvasive, common technologies are often made without consideration of their life-and-death implications.** Care of the life-threatened elderly involves a continuous series of treatment decisions which, individually, may seem so small and undramatic that their life-and-death implications are not even recognized. Decisions about the treatment of a life-threatening infection, even in severely debilitated and terminally ill people, frequently focus on choice of the appropriate antibiotic and omit explicit consideration of whether or not to treat.

FINDING: The physical, psychological, and financial stresses associated with life-sustaining treatments are great, not only for patients, but also for family members and caregivers.

The physical, psychological, and financial stresses imposed by the life-sustaining technologies OTA has studied differ with the technology, and their significance depends on the personalities, specific resources, and exigencies of each case. Also, the immediate and short-term stresses are different from those associated with chronic care. Some patients cope admirably with the discomforts and fears associated with acute care and, if necessary, with a technology-dependent lifestyle, but others respond to the anticipated stress by refusing treatment. Others start treatment but eventually request that it be withdrawn; they may be depressed or even suicidal.

Specific effects of the technologies OTA studied include inability to speak or eat (mechanical ventilation), discomfort and limited mobility associated with tubes and catheters (whether for ventilation, nutritional support, drug delivery, or dialysis), and a gamut of complications ranging from minor to life-threatening. For patients who are acutely ill, loss of sleep, disorientation, and anxiety are concomitants of hospitalization and medication that

may accompany all these treatments. Physical restraints, sometimes used for patients who are uncooperative or confused, are an additional source of distress. Fear of a new acute episode, loss of independence and control, dietary regimens, restricted activities, and financial worries may be among the long-term burdens for patients who are restored to medical stability. Comorbidities, reduced physiological reserve, and limited social support, i.e., characteristics of many elderly patients, may exacerbate any or all of these.

Family members and friends are also under great stress related to anticipatory grieving, financial burdens, and excessive demands on their time. Involvement in treatment decisions is likely to be filled with uncertainty, self-doubt, or perhaps guilt. If the duration of treatment is prolonged, and especially if the family has caregiving responsibilities, the lifestyle of family members may be radically changed. Emotional burdens may be especially great if the patient's condition or treatment impairs or precludes the ability to communicate or if treatment cannot be administered without physical restraints.

It is widely agreed that informed consent should include disclosure of the likely discomforts and restrictions attendant with use of these technologies. However, even if the patient is conscious and fully competent when the treatment decision must be made, the full impact of these treatments is difficult to predict and to convey. If the patient is unconscious or severely demented or confused, those entrusted with the treatment decision can only speculate about the patient's experience of pain or distress with (or without) any of these treatments.

Finally, caring for critically ill, terminally ill, or severely debilitated patients who may be treated with life-sustaining technologies is demanding and highly stressful for health care providers. In addition to the emotional load of dealing with very ill patients and grieving relatives, health professionals are constantly reminded of their own mortality and their fallibility. Emotional detachment from patients, avoidance of patients' families, and overuse of technologies are not uncommon responses. Impaired job performance and "burn-out" are also reported. Most health care professionals currently in practice received little or no training in the human aspects of death and dying; many are ill-equipped either to provide emotional support to dying patients or to cope with their own personal reactions.

Whether or not the experience of family members or caregivers should have any bearing on a treatment decision (or on who should be the surrogate) is an interesting ethical dilemma—which this assessment does not address. The point here is that patients may not be alone in their need for social and/or financial support.

FINDING: Currently, the most controversial life-sustaining technology is nutritional support. The highly emotional reaction to this technology obscures specific clinical, legal, and ethical questions that require resolution.

Of all the life-sustaining technologies OTA studied, nutritional support and hydration is the most troublesome for ethicists, clinicians, and the public. It is over this technology that advocates of "death with dignity" and the "right to life," as well as more moderate positions differ most sharply. The debate centers around the question of whether tube and intravenous feeding and hydration are "food and water" or a medical treatment. In the former view, the provision of artificial nutrition and hydration constitutes a basic aspect of human caring that should be withheld or withdrawn only when death is imminent or when it is not medically possible to provide them. In the latter view, these are medical treatments that can be withheld or withdrawn under the same circumstances as other life-sustaining technologies. These opposing views leave little common ground for the formulation of policy or for decisions regarding the care of individual patients.

Very little is known about persons on long-term nutritional support, especially in nursing homes. Anecdotal evidence and some recent research findings suggest that many patients on long-term tube feeding are cognitively impaired, but it is not clear why they are tube fed—whether it is because they resist hand feeding, because of swallowing difficulties, or for other reasons. Some people claim that nursing home residents are tube fed because hand feeding is too time-consuming. There are, however, no data to substantiate this claim.

Lack of information about cognitively impaired people on long-term tube feeding is related to the general lack of information about cognitive impairment in elderly people. Ongoing biomedical and behavioral research on Alzheimer's disease promises to provide some answers. However, much more needs to be learned about the physiological, psychological, and emotional aspects of dementia—particularly the late stages of dementing diseases—in order to understand why some patients with these conditions stop eating and refuse hand feeding.

The patient's formal consent is usually not obtained for nasogastric tube feeding—by far the most common mode of nutritional support—because it is not "invasive." Although nasogastric tube feeding does not involve surgery, some people consider it burdensome, particularly when it is used for prolonged periods, sometimes years. An unknown proportion of people who receive tube feeding, including some who are cognitively impaired, are physically restrained to keep them from pulling out the tube. This combination of factors would seem to indicate a need for very rigorous decisionmaking procedures that include methods for ascertaining the patient's treatment preferences whenever possible, appointment of a surrogate decisionmaker when necessary, and periodic review of both the need for and the method of treatment.

FINDING: Ongoing social and technological change will continuously alter the decisionmaking context.

The relatively brief history of life-sustaining technologies shows how rapidly and dramatically changes can occur in attitudes, expectations, and pol-

Table 3.—Legal Cases Involving Decisions About Withholding or Withdrawal of Life-Sustaining Treatment From Elderly Patients

State	Patient's age	Case	Technology
1977:			
Massachusetts	67	*Superintendent of Belchertown State School* v. *Saikewicz*	Chemotherapy
1978:			
Massachusetts	67	*In re Dinnerstein*	Resuscitation
Massachusetts	77	*Lane* v. *Candura*	Amputation of gangrenous leg
New Jersey	72	*In re Quackenbush*	Amputation of gangrenous legs
Tennessee	72	*State Department of Human Service* v. *Northern*	Amputation of gangrenous feet
1980:			
Massachusetts	78	*In re Spring*	Dialysis
Ohio	70	*Leach* v. *Akron General Medical Center*[a]	Mechanical ventilation
Florida	73	*Satz* v. *Perlmutter*	Mechanical ventilation
1981:			
New York	83	*In re Eichner*	Mechanical ventilation
California	67	*Foster* v. *Tourtellotte*	Mechanical ventilation
1983:			
New Mexico	65+[b]	*New Mexico ex rel. Smith* v. *Fort*	Dialysis
Washington	69	*In re Colyer*	Mechanical ventilation
Texas	65+[b]	*In re Guardianship Estate of Peterson*	Mechanical ventilation
1984:			
New York	88	*In re Moschella*	Mechanical ventilation
California	70	*Bartling* v. *Superior Court*	Mechanical ventilation
Florida	65+[b]	*John F. Kennedy Memorial Hospital Inc.* v. *Bludworth*	Mechanical ventilation
Ohio	70	*Leach* v. *Shapiro*[a]	Treatment against patient wishes/ mechanical ventilation
Arizona	82	*Lurie* v. *Samaritan Health Service*	Mechanical ventilation
Massachusetts	92	*In re Hier*	Nutritional support
New York	85	*In the Matter of Application of Plaza Health and Rehabilitation Center*	Nutritional support

Table 3.—Legal Cases Involving Decisions About Withholding or Withdrawal of Life-Sustaining Treatment From Elderly Patients—Continued

State	Patient's age	Case	Technology
1985:			
Washington, DC	71	*Tune* v. *Walter Reed Army Medical Center*	Mechanical ventilation
New Jersey	83	*In re Conroy*	Nutritional support
New York	70	*Saunders* v. *State*	Living will[c]
1986:			
New York	83	*In re Triarsi*	Mechanical ventilation
New York	79	*In re Vogel*	Nutritional support
New York	83	*In re Application of Kerr (O'Brien)*	Nutritional support
New Jersey	90	*In re Visbeck*	Nutritional support
Hawaii	73	*Wilcox* v. *Hawaii*	Nutritional support
Florida	73	*Corbett* v. *D'Alessandro*	Nutritional support
Virginia	65+[b]	*Hazelton* v. *Powhatan Nursing Home, Inc.*	Nutritional support
Arizona	70	*Rasmussen* v. *Fleming*	Nutritional support/resuscitation
Ohio	79	*Galvin* v. *University Hospitals*	Treatment against patient wishes/ resuscitation
California	75	*Cantor* v. *Weiss*	Nutritional support
1987:			
New York	79	*Workman's Circle Home and Infirmary for the Aged* v. *Fink*	Nutritional support
California	92	*Gary* v. *California*	Nutritional support
New Jersey	91	*McVey* v. *Englewood Hospital Association*	Treatment against patient wishes/ mechanical ventilation

[a]The 1980 case *Leach* v. *Akron General Medical Center* concerned a petition by Mrs. Leach's husband for an order to discontinue mechanical ventilation for her. The 1984 case *Leach* v. *Shapiro* involved an action for damages against the doctor and hospital for the time Mrs. Leach was on mechanical ventilation. Both cases are discussed in ch. 3.
[b]The precise age of the patients in these cases is not known, although they are known to be over 65.
[c]The patient sought prior judicial validation of her living will so that it could be carried out without delay if her condition deteriorated to the point at which she would want to refuse life-sustaining treatment.

SOURCE: Office of Technology Assessment, 1987.

icies that determine their use. These changes are driven by a variety of social and technological factors that are in constant flux and that are often unanticipated.

At both the individual and societal level, decisions about the use of life-sustaining technologies for elderly people will be influenced by (and, in turn, will influence) changes in a wide variety of factors, including technological capabilities, scientific knowledge, medical education, economic conditions, public policies and laws, and public attitudes and expectations. Factors that have attracted considerable attention in recent years include the growth and aging of the elderly population, efforts to contain health care costs, and concern about the quality of life. Decisions about the use of life-sustaining technologies will also be influenced by the increasing level of education and sophistication among the elderly population, increased competition in health care, and an oversupply of physicians. Comprehensive national health insurance, a solution to the "malpractice crisis," and prevention of dementia are examples of more distant but equally significant future possibilities.

Improvements in existing technologies and new treatment modalities could improve the efficacy of treatments, reduce the chance of complications, and increase patients' comfort and independence. Technological developments might either raise or lower the cost of treatment. Other developments, including improved methods of pain control, and increased portability and self-care, as well as innovations like artificial eyes and ears, will improve the quality of life for chronically ill, disabled, and technology-dependent people. These marginal improvements and innovations could alter the balance of benefits and burdens of a particular technology and change attitudes about sustaining life in persons who are elderly and disabled. In some cases, treatment decisions might become easier and standards of practice might change, leading to increased use of life-sustaining technologies.

Some existing technologies will be wholly replaced. Just as kidney transplants eliminate the need for dialysis in individual patients, other organ transplants or artificial organs may eventually obviate the need for other life-sustaining technologies. Very widespread use of such "definitive" technologies could render today's "halfway technologies" obsolete. Further in the future, effective preventive strategies might have even more profound effects on human health and longevity. However, with respect to decisionmaking, the effect of this kind of technological development will be merely to push problems further into the future. If we learn to cure heart disease, we will still face cancer, stroke, and other potentially fatal diseases. We might eliminate one cause of death after another, but never all of them.

Neither the development of new technologies nor improvements in existing technologies are likely to make the fundamental issues of access, quality, and cost of care, or the decisionmaking dilemmas these create, go away. Instead, change will be in the foci and details of current ethical, legal, and clinical debates. OTA's analysis shows that the current intense interest in nutritional support follows more than a decade of controversy and court

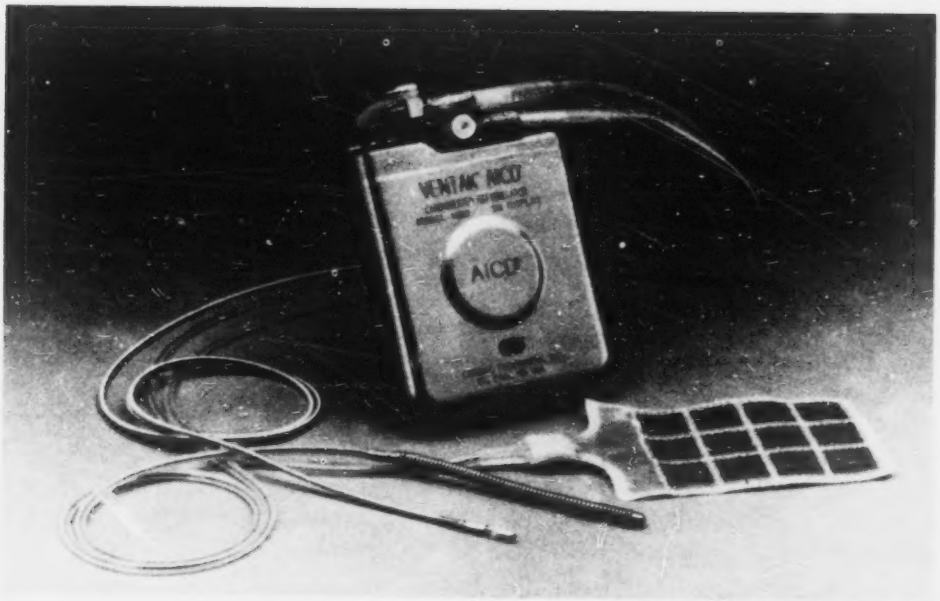


Photo credit: Cardiac Pacemakers, Inc.

The implantable defibrillator received FDA approval late in 1985 and was approved for Medicare coverage early in 1986. The pulse generator, a device the size of a cigarette pack, monitors cardiac activity and treats tachycardia and fibrillation by applying a counter shock through wire leads that are attached to the heart.

cases focused on mechanical ventilation. A possible next center of controversy is antibiotic therapy, which is only now gaining recognition as a life-sustaining treatment that raises serious issues. Similarly, changes in technology and in health services delivery will shift concern from the hospital to community settings and transfer more decisionmaking responsibility from physicians to other health care personnel and to lay caregivers.

In addition, **social and technological change will bring some new questions and intensify some of the current problems.** For example, as both the law and medical practice change, new kinds of legal challenges may arise. A recent instance in which physicians were charged because they instituted unwanted treatment is said to have opened the door to a new set of legal actions. The old problems of cost and access to care may be exacerbated if, as many people predict, the cost of providing the full range of theoretically beneficial treatments continues to increase. Particularly high cost will be associated with the care of individuals enabled to survive much longer than currently possible. Continuing high cost (and increasing cost) could lead to a more prominent role of third-party payers and government in health care decisionmaking.

Other pertinent developments will not change the basic decisionmaking problems but do promise to help us sort through difficult choices. These include the procedures, policies, and technological developments that aim to supply more complete information on which to base decisions and/or

a more systematic way to assimilate it and reach an informed conclusion. These range from patient education to health professions education and from computerized decision support systems to ethical analysis.

CONGRESSIONAL ISSUES AND OPTIONS

The following issues and options are derived from information summarized in this chapter and presented in detail in the full report. They address problems that are common among several or all of the life-sustaining technologies OTA studied and that are realistic foci for congressional oversight and legislative activity. Problem areas that are unique to one or another technology and those that do not suggest Federal involvement are presented in the findings and implications at the end of each of the respective chapters. Ultimately, resolution of the diverse problems associated with the use of life-sustaining technologies for elderly people and maximization of the potential good these technologies can bring will require the creativity and cooperation of philosophically and professionally diverse factions.

The first pair of issues and accompanying options addresses research needs that relate to all of the subsequent issues. These include statistical data for improved health care planning and delivery and basic research to expand the scientific knowledge base. The next pair of issues and options addresses the concern of the requesting congressional committees about access to life-sustaining treatments and how access is affected by age, availability of reimbursement, and setting. The third issue area addresses what Congress might do to reduce problems in individual decisionmaking about the use of life-sustaining treatments. The two final issues and options address questions that arose in the course of this assessment about the safety and efficacy of life-sustaining technologies and the quality of care provided for elderly people once a decision has been made to provide, withhold, or withdraw life-sustaining technologies.

Associated with each policy issue are several options for congressional action, including in each case, no action. The order in which the options are presented should not imply their priority. The options are, for the most part, not mutually exclusive. In fact, a careful combination of options might produce the most desirable effects. Further, while these issues address life-sustaining treatment for elderly persons, many of them are applicable to patients of all ages.

The issues and options presented here are realistic foci for congressional oversight and legislative activity. Numerous other issues fall more appropriately within the activities of nongovernmental bodies. Ultimately, resolution of the various problems associated with the use of life-sustaining technologies for elderly people and maximization of the potential good these technologies can bring will require the creativity and cooperation of philosophically and professionally diverse factions.

Research

ISSUE 1: What could Congress do to strengthen and expand the statistical database on the utilization and costs of life-sustaining technologies?

1.1 Take no action.

1.2 Provide funds and instruct HCFA to conduct studies on the utilization of and expenditures for life-sustaining technologies in hospitals, nursing homes, and home care.

1.3 Instruct HCFA, the National Center for Health Statistics, and the Veterans Administration (VA) to develop and employ standardized methods for calculating and reporting utilization and costs of life-sustaining technologies.

Several factors argue against a Federal role in the collection of additional health statistics and/or establishment of a databank on the use of life-sustaining technologies. First, inaction at the Federal level (i.e., Option 1.1) would avoid the expenditures related to new data collection efforts. Additional medical recordkeeping and changes in reporting methods might be opposed by the institutions and individuals who are asked to provide the data. In addition, some observers fear that a recordkeeping system that specifies cost and reimbursement for particular technologies could lead to inappropriate economic pressures to alter treatment patterns.

On the other hand, a major finding of this assessment is that neither the magnitude of current problems nor predictions of future demand can be adequately estimated with existing data sources. (The scarcity and unreliability of available data are substantial for young as well as elderly patients.) Data on the utilization of and expenditures for life-sustaining technologies come mainly from small case studies whose results cannot be aggregated or generalized. The notable exception is dialysis, for which good utilization and expenditure data are *now* maintained, but for which the absence of data prior to Medicare coverage contributed to gross underestimates of the eventual demand for this treatment. Improved data would help inform public policy and, to the extent that the necessary recordkeeping makes clinical decisions more explicit, could also improve decisionmaking in individual cases.

Sample surveys of Medicare patients and elderly Medicaid patients who receive life-sustaining technologies (Option 1.2) would be a relatively easy and relatively inexpensive way to expand the statistical database on utilization and Federal expenditures. Careful consideration must be given to determining which life-sustaining technologies warrant this attention. At a minimum, for each selected technology, the studies should provide data on: the patient's age, diagnoses, treatment settings, clinical outcome, discharge status, and payments by Medicare and/or Medicaid. Information

on expenditures by private insurers, patients, and any unpaid charges would also be desirable, to complete the cost picture. Parallel data on elderly patients in hospitals, nursing homes, and in their own homes would provide a rather comprehensive data set useful for a variety of analyses. Ideally, the data would permit cross-sectional or longitudinal analysis, comparisons among subgroups within the elderly population, and comparisons of utilization and costs in different settings. Improved information about the current situation would be essential input to any Federal policy decisions about limiting or expanding health care services, payment, or training. If maintained continuously or updated periodically, these data could be the foundation for predictions of future demand for and cost of providing particular technologies. The arguments against Option 1.2 are the same as those in support of Option 1.1.

Option 1.3 addresses the noncomparability of utilization and cost data that are currently available. Problems in utilization data result from different definitions of such terms as "chronic" or "prolonged" use, dissimilar age categories, and variations in codes for the pertinent medical and surgical procedures. "Cost" data sometimes represent charges, sometimes expenditures, and exactly what is included is seldom specified. The main argument against this approach is that the definitions and methods developed may not adequately fit the diverse needs of potential users. To reduce this possibility, standardized definitions of utilization and costs should be developed with input from all interested parties—especially hospitals, insurers, patients, health economists, and policymakers.

ISSUE 2: What could Congress do to strengthen and expand scientific and clinical knowledge related to the use of life-sustaining technologies, especially for elderly people?

2.1 Take no action.

2.2 Authorize and appropriate funds administered through the National Institute on Aging (NIA) for studies of life-threatening conditions in the elderly and the physiological and psychological responses of elderly patients to alternative treatments.

2.3 Provide research funds administered through NIA to coordinate work on the development of measures that better reflect the health status and reserve capacity of elderly people than does chronological age.

2.4 Authorize and appropriate funds through the Department of Health and Human Services (DHHS) or NIH to develop and test patient classification systems and other aids to clinical decisionmaking.

2.5 Authorize and appropriate funds to support an NIH research planning conference focused on the care of elderly persons with life-threatening conditions.

Option 2.1 assumes that existing Federal support for technology assessment and basic research related to life-sustaining technologies is adequate

and appropriately directed, that adequate non-Federal support is available, or that additional research would not reduce problems related to the use of life-sustaining technologies. Proponents of additional research argue that little research has been focused on these topics and that information is needed to reduce inappropriate and ineffective utilization of life-sustaining technologies. Research would require additional Federal expenditures or shifting of funds from other areas. However, potential benefits, in terms of improved patient selection and improved quality of care, as well as potential reductions in the cost of care that is provided, might outweigh the costs associated with research.

Very little research has focused on the relationship between advanced age and the clinical outcomes of life-sustaining technologies. The resulting information gaps contribute to clinical uncertainty and prognostic errors, as well as suboptimal care and poor outcomes. Added Federal support for research on these topics (Option 2.2), especially prospective and longitudinal studies, could lead to improved understanding of the factors associated with different clinical outcomes, including longevity. This knowledge could lead to the development of age-indicated modifications in treatment that could, in turn, lead to increased survival of elderly persons with life-threatening conditions, with improved functional capacity, reduced complications, and less recidivism.

It has been well established that physiological changes occur at different rates and to different extents in different people, with the effect that individuals are *increasingly dissimilar* as they age. While many physicians now recognize that chronological age masks this heterogeneity, age remains the simplest single indicator of physiological status. Basic research on age-related physiological change and response to stress, directed toward the development of alternative measures of health status and reserve capacity (Option 2.3) might lead to improved accuracy in patient assessment and prognosis.

Option 2.4 proposes Federal support for the continuing development and testing of patient classification systems and other aids to clinical decisionmaking. Some of these systems, currently experimental, show considerable promise for identifying patients who are likely to benefit from treatment and patients who are likely to die despite treatment. Refinement of these systems and/or development of new approaches could reduce ineffective use of life-sustaining technologies.

Another approach to providing information that could potentially improve decisionmaking would be sponsorship of an NIH research planning conference, as suggested in Option 2.5. The conference would bring together experts in geriatrics and in critical care, medical decisionmaking, health services, and health law, with the goal of specifying and prioritizing areas of research on the care of the life-threatened elderly. A consensus about key issues would direct Federal funding to the most fruitful areas, and the visibility of such a conference could also help to stimulate private funding for identified priority areas.

Access to Care

ISSUE 3: What could Congress do to protect elderly persons from possible age-based discrimination in access to life-sustaining medical treatments?

3.1 Take no action.

3.2 Provide funds and instruct HCFA to conduct studies of hospital and nursing home practices regarding the offering of life-sustaining technologies to elderly patients.

3.3 Instruct HCFA to expand Medicare reimbursement for life-sustaining medical care.

(Also see Options 2.3, 5.3, and 6.4.)

Whether or not Federal action to prevent possible discrimination is warranted at this time depends on one's evaluation of the current situation. One goal of recent public policy is to protect the equal rights of all citizens, without regard to race, sex, or *age*. Ensuring equal access to needed health care is one of the responsibilities of policymakers. However, because health care resources are not unlimited and because aging is universal, "equal" access can include different interpretations of the kinds of care that must be offered, under what circumstances, and for how long. Some people argue that Medicare, because it provides health care mainly to elderly persons, is itself inequitable. On the other hand, anecdotes about limited care for hospitalized Medicare patients have stirred public concern and congressional attention. The extent to which elderly persons might be denied access to life-sustaining technologies because of their age is not known; however, limited Medicare hospital reimbursement, health professionals' ignorance of the good prognosis for many elderly patients, and residual ageism create considerable potential for age discrimination in access to these treatments.

Studies proposed in Option 3.2 would provide information about the extent to which Medicare patients and elderly Medicaid patients are offered various life-sustaining technologies in hospitals and nursing homes. This information would enable peer review organizations (PROs)[6] or other overseers to identify cases in which life-sustaining technologies were not accessible. It would not, however, be possible to draw from this conclusions about age-based discrimination unless comparable information were available for younger patients as well. Requiring sampled providers to keep records of all treatments offered to patients would benefit those patients by encouraging physicians to entertain and to discuss with patients all reasonable treatment options.

[6]The function of PROs is to review the appropriateness of hospital admission for Medicare patients, approve payment, and monitor quality of care. On appeal, PROs also review individual cases in which admission or payment is thought to be inappropriately denied, and cases in which discharge is thought to be premature.

Current cost-containment pressures and limited Medicare reimbursement provide hospitals and physicians financial disincentives to admit and to aggressively treat Medicare patients whose costs are likely to exceed what Medicare will pay under PPS. Option 3.3 would remove or reduce those financial disincentives. Adjustments could be made in the level of reimbursement for DRG categories that frequently involve life-sustaining technologies, by creating new technology-specific reimbursement categories, by adding a severity of illness measure to all DRGs, by increasing the age adjustment factor that already applies to some DRGs or by raising outlier rates. Such actions would be expensive and difficult to justify when there is no proof that age-based discrimination is a serious problem. However, some people would view the protection of access to health care as important enough to justify a preventive approach.

Option 2.3 would reduce opportunities for treatment decisions based on unjustifiable generalizations about old age. Options 5.3 and 6.4 would educate patients and providers, respectively, to be better advocates for themselves and for their elderly patients.

ISSUE 4: What could Congress do to increase the availability of life-sustaining technologies in nonhospital settings?

4.1 Take no action.

4.2 Instruct HCFA to provide Medicare coverage for life-sustaining antibiotic therapy and short-term nutritional support outside the hospital setting.

4.3 Instruct HCFA to increase Medicare home health care coverage for personnel who provide needed services for Medicare patients dependent on life-sustaining technologies in their own homes.

4.4 Instruct HCFA to encourage the States to raise Medicaid reimbursement available to nursing homes that hire highly skilled personnel in order to provide life-sustaining technologies.

4.5 Authorize and appropriate funds to DHHS for the support of research and demonstration projects regarding the use of life-sustaining technologies in nonhospital settings.

Current medical practice and reimbursement policy favor the use of hospitals, and often their ICUs, for application of most of the life-sustaining technologies OTA studied. For patients who are medically stable and who no longer require the resources of a hospital, care in another setting is generally less costly and facilitates a less restricted lifestyle. Therefore, most people think it would be beneficial for patients, as well as more efficient, if utilization of life-sustaining technologies were shifted as much as possible to nonhospital settings (Option 4.1). Expanded availability of life-sustaining technologies outside of hospitals could, however, lead to inappropriate use, with consequent increased cost. Further, the quality of care could be jeopardized in these relatively unsupervised settings.

OTA found that some patients who could safely be treated in alternate settings are confined to hospitals because of inability to pay for services elsewhere. For some technologies, e.g., ventilation, the problem is that the unreimbursed portion of care, while it may be a small percentage of the total cost, is often still very high. For two of the technologies discussed in this assessment, life-sustaining antibiotic therapy and short-term nutritional support, Medicare reimbursement outside the hospital is completely unavailable. Option 4.2 suggests expansion of Medicare benefits to cover these technologies. Option 4.3 goes a step farther, proposing Medicare reimbursement for the personnel needed to provide any life-sustaining treatments outside of hospitals. Among these personnel are health professionals (e.g., respiratory therapists, professional nurses), and nonprofessionals (aides).

Option 4.4 addresses the current difficulty in nursing homes of hiring staff who have the necessary skills and credentials to provide complex care. Most nursing homes do not admit patients who are receiving mechanical ventilation, intravenous antibiotics, or TPN, and most are not equipped to provide these treatments to residents who need them. Inadequate and unpredictable reimbursement make it difficult for nursing homes to develop staff and services and, thus, limit out-of-hospital options for persons who are medically ready to be discharged from hospitals. Some nursing homes that do provide care for technology-dependent persons have negotiated special reimbursement arrangements with Medicare or Medicaid on a patient-by-patient basis. For patients who are eligible for Medicare nursing home benefits, coverage could be extended beyond the current 100-day limit. For technology-dependent Medicaid patients in nursing homes, HCFA could offer States incentives to increase reimbursement.

Information regarding the relative benefits and problems in providing life-sustaining technologies in alternative settings is piecemeal and largely anecdotal. Option 4.5 would support research and demonstration projects to clarify the types of patients for whom alternatives to the hospital (and, within hospitals, alternatives to the ICU), are safe, economical, and contribute to the patient's quality of life. Such projects could also provide information regarding the supportive services patients need in different settings, alternative methods for providing them, and the relative costs and benefits. One possible site for such projects is the teaching nursing home. An important component of such programs would be their educational benefits, i.e., through the opportunity to train health professionals within the institutions where projects go on and the dissemination of results to health professionals in other institutions.

A main argument against Options 4.2 through 4.5 is that liberalization of reimbursement for home care and nursing home care of technology-dependent patients might create substantial new demand for services and attendant new costs to the Federal Government. In addition, some people fear that quality of care cannot be assured outside the hospital. Other difficulties relate to decisions about whether coverage should be for all life-sustaining technologies or only designated ones (i.e., Option 4.2), which personnel should be reimbursed for which services (Option 4.3), and whether

particular treatment settings, rather than all nonhospital settings, are to be equally encouraged.

Decisionmaking

ISSUE 5: What could Congress do to protect the rights of elderly patients in decisions about the use of life-sustaining interventions?

5.1 Take no action.

5.2 Authorize and appropriate funds for research and demonstration projects that will provide information about current decisionmaking practices, problems, and possible solutions.

5.3 Support education of the public regarding their rights as patients and mechanisms for implementing these rights.

5.4 Instruct HCFA, the VA, and the Department of Defense to require Federal health care facilities and health care facilities that are certified to treat Medicare and Medicaid patients to: 1) record in a patient's record any advance directive the patient presents, and 2) honor that directive.

5.5 Instruct HCFA, the VA, and the Department of Defense to require health care institutions that receive Medicare and Medicaid reimbursements as well as all Federal health care institutions to: 1) develop written policies describing the procedures they will follow in making a decision about life-sustaining technologies, and 2) communicate these policies to all patients.

5.6 Develop Federal legislation regarding advance directives and procedures for the identification of surrogate decisionmakers.

(Also see Option 6.4.)

The proper role of the Federal Government in health care decisionmaking is very controversial, with opinions ranging from *no* role to a direct, *intimate* role (as in the original "Baby Doe" regulations). Governmental involvement in the substance of treatment decisions for the life-threatened elderly would meet strong opposition from health professionals and from patients of all persuasions. More widely accepted roles for Government would focus on either the provision of information (Option 5.2 and 5.3), the establishment and protection of decisionmaking procedures (Option 5.4 through 5.6), or both. However, some people oppose all forms of governmental involvement, arguing that decisionmaking procedures as well as substantive decisions are the responsibility of qualified health care professionals (Option 5.1).

OTA's findings suggest several kinds of information about decisionmaking that could help reduce current problems. Option 5.2 calls for the collection and analysis of descriptive information about how decisions are made with regard to the use of life-sustaining technologies for elderly people. This kind of research would provide evidence on the extent to which elderly persons participate in decisions about the use of life-sustaining treatments,

identify the reasons patients' wishes are not always implemented, and would identify any subgroups of the elderly population (e.g., extremely old persons, demented persons, nursing home residents) whose rights may need greater protection. Such research would also contribute to determining the practical strengths and weaknesses of different kinds of advance directives and different decisionmaking processes. However, some people might perceive this kind of research as an invasion of privacy.

Option 5.3 addresses the current scarcity of public education regarding patients' rights, the importance of making known one's wishes regarding life-sustaining treatments, and available mechanisms for formalizing these wishes. This option assumes that such education would result in more people preparing some type of formal advance directive (e.g., living will or durable power of attorney) or, at least, discussing with their family or physician their personal views regarding life-sustaining treatment. Increasing the number of persons whose wishes are known should result in an increase in the number of patients whose wishes are honored. Some people have suggested that having a clear directive from the patient is the single best way to reduce unnecessary health care expenditures. Opposition to such educational efforts might come from those who fear that the educators would advocate particular positions.

Options 5.4 and 5.5 reflect OTA's finding that, in many institutions, the approach to decisionmaking about the use of life-sustaining technologies is ad hoc. In most hospitals and nursing homes, there is no mechanism for determining or registering a patient's treatment preferences before the need for a life-sustaining technology arises, when it may not be possible to consult the patient. In some cases, health care providers are not aware that a patient who is decisionally incapable has an advance directive. Even if they are aware of the advance directive, they do not always follow it.

Formal institutional policies for decisionmaking could help protect a patient's right to participate in treatment decisions and clarify the roles and responsibilities of other participants in the decision (e.g., families, ethics committees). Institutional policies would not necessarily offer any legal protection to patients, institutions, or individual caregivers, but they could potentially acquire considerable authority as they evolve into standards of practice.

The Federal Government could require health care institutions that receive Medicare and Medicaid reimbursements and Federal health care institutions to develop formal institutional policies for decisionmaking (Option 5.5). Although many parties favor the establishment of policies for decisionmaking at the institutional level, it is not clear whether such policies should be required by the Federal Government. The number of hospitals, nursing homes, and other health care facilities that have formal institutional policies for decisionmaking appears to be growing. The recently announced JCAH requirement that hospitals and nursing homes must have a policy for decisions about resuscitation in order to be accredited by JCAH is expected to further this trend. Thus, some people believe that there is no need for a Federal requirement for institutional policies for decision-

making. Other people believe that a Federal requirement is needed to ensure that most, if not all, health care facilities have such policies in place.

Even if the Federal Government were to require health care institutions to have policies for decisionmaking, it is unclear whether the requirement should address the content of those policies or whether the content of the required policies should be left to the discretion of each institution. If agreement is reached that content should be addressed by the Federal Government, it is unclear whether the requirement should specify questions the policies must answer (e.g., how a patient's decisionmaking capacity will be assessed or how a surrogate will be selected) or decisionmaking procedures that should be followed. Some people believe that the content of decisionmaking policies should be determined by individual institutions because of differences in their purposes, practice environments, and patient populations. Others believe that at least minimum standards should be included to protect patients' rights and ensure some consistency across jurisdictions and institutions. Selection of such standards would be difficult because of disagreement about appropriate decisionmaking practices.[7]

Option 5.6 suggests Federal legislation to authorize advance directives (living wills and durable powers of attorney for health care) and to specify procedures for identifying surrogate decisionmakers for patients who are not decisionally capable and who have no advance directive. Federal legislation to authorize advance directives would make these methods of documenting an individual's treatment preferences available to all Americans, including those who live in States that have not enacted statutes allowing advance directives. Federal legislation could ensure that a living will or durable power of attorney for health care executed in one State would be accepted in other States. Proponents of advance directives, who view them as an important safeguard of patient autonomy, would probably welcome such legislation. Yet disagreement about specific provisions of advance directives, e.g., whether they should allow withholding or withdrawal of life-sustaining nutrition, hydration, and medications and whether they should allow withholding or withdrawal of treatment from persons who are not terminally ill, would complicate the development and enactment of such legislation.

People who believe that life should be sustained whenever it is technically possible to do so would probably oppose Federal legislation authorizing advance directives because the directives usually allow withholding or withdrawal of treatment. Some people would also object to Federal legislation in an area that has traditionally been governed by the States and might prefer Federal actions that encourage States to enact statutes authorizing advance directives. Others might prefer that the Federal role be limited to support of public education about advance directives (Option 5.3).

Federal legislation specifying procedures for identifying a surrogate decisionmaker for patients who are decisionally incapable and have no advance directive and defining the role and responsibilities of the surrogate could

[7]As a follow-on to this assessment, OTA has commissioned a report on institutional policies for decisionmaking that will consider these questions in more detail. That report will be available in early 1988.

reduce confusion about the legality of existing decisionmaking practices for these patients. Such legislation might be modeled after the family consent laws now in effect in 15 States. Alternatively, the Federal Government could require health care instititutions to have formal policies defining procedures for surrogate decisionmaking as a part of the institution's policy for decisionmaking, as in Option 5.5. Objections to these approaches are similar to objections to Option 5.5.

Quality of Care

ISSUE 6: What could Congress do to improve the quality of care associated with the use of life-sustaining technologies for elderly people?

6.1 Take no action.

6.2 Instruct the Federal agencies engaged in technology assessment and clinical trials, i.e., the National Center for Health Services Research and Health Care Technology Assessment's Office of Health Technology Assessment (OHTA), the Food and Drug Administration (FDA), NIH, and OTA to make studies of life-sustaining technologies a priority.

6.3 Provide Federal funds or tax incentives for research and development of improved life-sustaining technologies (equipment and products), including refinements that simplify operation and maintenance.

6.4 Authorize and appropriate funds to DHHS and the VA to support education and training as well as special practice models for health professionals who care for the life-threatened elderly.

6.5 Authorize and appropriate funds for DHHS to develop model programs offering comprehensive support services to technology-dependent elderly persons who need them.

This assessment has raised both general questions about efficacy and safety of some life-sustaining technologies and questions that are specific to the use of these technologies for elderly patients. Problems arise from deficits in the knowledge base, the technologies, and the personnel. Numerous activities that have potential benefits in terms of ensuring the efficacy and safety of life-sustaining technologies for elderly patients are already underway. These include the regular activities of FDA, technology assessments by OTA and OHTA, clinical studies by NIH, and support for health professions training, including programs to expand education and training in geriatrics and gerontology. Some would conclude that these activities are adequate. However, with respect to special needs of the life-threatened elderly, none of these programs goes very far.

Questions have been raised about the reliability of some equipment and products and about undue complexity (and, therefore, cost) of others. These questions suggest the need for assessment of life-sustaining technologies in addition to those OTA has studied and for correction of identified problems. Option 6.2 would provide information about any problems related

to particular medical technologies used to sustain life. This would inform policy decisions about whether or not a particular technology ought to be widely available, or reimbursed, and clinical decisions about its use for individual patients. A practical drawback to Option 6.2 is that there are a large number of life-sustaining technologies, and new ones being developed, and only a fraction of them can be assessed. Also, unless tied to approval by FDA or to reimbursement decisions, the results of these assessments might have little effect. Option 6.3 would encourage R&D in Federal laboratories, provide grants to universities and major medical centers, and support special incentives to the private sector to improve existing technologies and to develop reliable and relatively simple technologies suitable for use in the home or nursing home.

Option 6.4 would support curriculum development, instruction, and practice models focused on: 1) geriatrics and gerontology, and 2) humanistic care of the dying, in order to simultaneously increase the supply and upgrade the capabilities of pertinent health professionals. Programs would target physicians, nurses, and allied health professionals still in training as well as health professionals already in practice.

The Federal Government currently supports education and training in geriatrics and gerontology through programs of the NIA, National Institute of Mental Health, Administration on Aging, Health Resources and Services Administration (HRSA), and the VA. Despite dramatic increases in the numbers of physicians and other health professionals committed to geriatrics, serious manpower shortages and barriers to recruitment suggest that more needs to be done. Moreover, existing education and training does little to specifically prepare physicians or nurses to care for elderly persons who become candidates for life-sustaining technologies. Pertinent curricular innovations, e.g., clinical ethics, death and dying, health law, decision analysis, assessment of patients' decisionmaking capacity, and interdisciplinary teamwork, are relatively new and, under current cost-containment strategies, their continuance is threatened. There is no cross-training between specialists in geriatrics and specialists in critical care. Many people assume that providing more education and training in these areas would improve the quality of care for the life-threatened elderly. There has been, however, very little research to evaluate the benefits of this kind of education, and, therefore, limited evidence that such programs have a significant effect on treatment outcomes.

Option 6.5 recognizes that many patients who are chronically dependent on a life-sustaining technology have unmet needs for financial and other kinds of assistance, such as attendants, transportation, special equipment, architectural modifications, group purchasing of medical supplies, etc. New Federal programs that target specific groups of patients for special benefits could be criticized as perpetuating a disjointed approach to health care, and new expenditures would be required. In France and England, comprehensive programs for ventilator-dependent patients have proved to be cost-effective and of great benefit to patients, enabling some technology-dependent persons to live in their own homes, with relative independence and maximum quality of life.

ISSUE 7: What could Congress do to improve the quality of care for people from whom life-sustaining treatments are withheld or withdrawn?

7.1 Take no action.

7.2 Instruct HCFA to extend eligibility criteria for hospice care and palliative treatments, to make them more widely available.

7.3 Appropriate funds and direct NIH or HRSA to support research and training to study the dying process and to develop methods of palliative care for patients from whom life-sustaining technologies have been withheld or withdrawn.

Federal involvement in research, health professions education, and reimbursement for health care have greatly benefited patients who want aggressive medical treatment. Good care has been widely available and the financial barriers largely removed. However, for patients from whom life-sustaining technologies are withheld or withdrawn, treatment options are undeveloped, and resources are scarce. The single focus of Federal efforts on behalf of these patients is hospice care and the provision of limited hospice benefits under Medicare.

The hospice model of care was developed to meet the physiological and psychological needs of patients who have been diagnosed as terminally ill and who choose to forgo aggressive treatment. Most hospice patients are victims of incurable cancers who consciously requested this kind of care. Hospice care has not been available in this country to persons who cannot make decisions about their care and those who have not been designated terminally ill. The potential benefits for some such patients, for example, severely demented patients who cannot be dialyzed, decisionally capable ESRD patients who choose to discontinue dialysis, and patients with chronic obstructive pulmonary disease who refuse mechanical ventilation, have not been studied. Option 7.2 would make hospice care more widely available.

Anecdotal evidence suggests that, following a decision to withhold or withdraw life-sustaining technologies, patients are sometimes essentially abandoned. Health professionals may simply have nothing to offer these patients. Therapeutic options are exhausted or rejected; methods and resources for pain control and bereavement counseling are undiscovered, illegal, or unfunded. Option 7.3 is to support behavioral, pharmacological, and health services research geared toward discovering and then meeting the needs of this group of patients. For these people, Option 7.3 would provide some answers about the potential benefits of existing forms of hospice care, develop options to the use of life-sustaining technologies, and then train health care professionals in these methods. The cost of such programs might be returned many times by reduced expenditures for life-sustaining technologies. Of all the many research needs identified in this assessment, those referred to in Option 7.3 are among the most important.

GUIDE TO THE FULL REPORT

OTA's full report entitled "Life-Sustaining Technologies and the Elderly" is a 450-page volume consisting of this summary document (which appears as chapter 1) plus nine additional chapters and eight appendices.

Chapter 2 presents the "context of the report," a broad overview and analysis of the major historical and sociological events that brought us to where we were when this assessment was requested. Legal, ethical, and scientific developments are reviewed, along with discussion of changes in the health care system and implications of the aging of the population.

Chapters 3 and 4 review, respectively, the legal and ethical issues affecting decisions about the use of life-sustaining technologies. Federal and State statutes, case law, patients' rights, and methods to ensure them are described, and problems are analyzed. Chapter 4 provides examples of the kinds of ethical dilemmas that frequently arise when life-and-death treatment decisions must be made and analyzes them in the context of the major philosophical theories of justice and the distribution of scarce resources. It also includes discussion of the ethical arguments for and against using age as a criterion in allocation decisions.

The selected life-sustaining technologies are individually considered in chapters 5 through 9. Each of these chapters contains detailed information describing the technology and its application, indicating what is known about current utilization, costs of care, and the clinical outcomes. How decisions are made about the use of the technology, including specific ethical, legal, and clinical problems bearing on decisionmaking, as well as the the socio-psychological and economic impacts of these decisions are discussed. Patterns of use, including distribution across different kinds of health care settings and indications of changes in use are described. Also included are pertinent comparisons with practices and/or programs in other countries. True case vignettes portray the wide range of elderly patients receiving each technology.

Chapter 10 addresses a variety of issues related to the supply and the professional preparation of the many professional caregivers involved in life-sustaining treatments for elderly people. It describes the emergence of geriatric medicine and gerontological nursing, and the interface of geriatrics with critical care. Problems in and benefits of interdisciplinary collaboration are discussed in relation to the goal of improving the quality of care for life-threatened elderly people.

The appendices include a paper on future developments in life-sustaining technologies, an international directory of bioethics organizations, proceedings of an NIH conference on decisions about mechanical ventilation, technical information on nutritional assessment and antibiotics dosages for elderly people, and a glossary of acronyms and terms.

The background papers and other contractor reports produced for this assessment are available from the National Technical Information Service (5285 Port Royal Road, Springfield, VA 22161; 703/487-4650). They are compiled in the following five volumes: 1) "The Technologies, Part 1" (resuscitation, ventilation, dialysis); 2) "The Technologies, Part 2" (nutritional support, antibiotics, future developments); 3) "Legal and Ethical Issues, Manpower and Training, and Classification Systems for Decisionmaking;" 4) "Use of Life-Sustaining Technologies in Other Countries;" and 5) "Philosophical, Legal, and Social Aspects of Surrogate Decisionmaking for Elderly Individuals."

NOTE: Copies of "Life-Sustaining Technologies and the Elderly" can be purchased from the Superintendent of Documents, U.S. Government Printing Office, Washington, DC 20402. The full report, GPO stock No. 052-003-01074-7, is available for $19.00 per copy. The summary document, GPO stock No. 052-003-01078-0, is $2.00 per copy.

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(NOTE: For brief descriptions of these studies in progress, see OTA booklet on "Assessment Activities"—available from OTA's Publications Office, 224-8996.)

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